# EXPLORING THE CONTEXT AND ROLE OF QUALITY OF CARE ON HIV OUTCOMES AMONG FEMALE SEX WORKERS IN THE DOMINICAN REPUBLIC

by
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**Abstract**

Female sex workers (FSWs) experience a substantially disproportionate burden of HIV. In the Dominican Republic (DR), FSWs have nearly five times greater odds to be living with HIV compared to other adults. Despite interventions focusing on facilitating FSWs' engagement in the HIV care continuum, ART adherence and viral suppression remain sub-optimal. It is thus important to assess the contributing role of quality of HIV care on HIV outcomes and explore the mechanisms for improving this care as a means to address FSWs' pathway to viral suppression.

Thematic analysis was used to explore the dynamics contributing to the quality of HIV care among FSWs living in the DR using two rounds of in-depth interviews (IDIs) (n=20 per round) and clinic assessments (n=11). Next, drawing from survey data (n=211), multivariable logistic regressions were used to explore the associations between select individual, provider and clinic level factors, and ART adherence and viral suppression. Lastly, the role of peer navigation in enhancing the quality of HIV care was explored via IDIs and survey data.

Results highlighted the influence of treatment literacy, relational aspects of the HIV care experience, availability of resources, and the cost of care on the quality of HIV care experienced by FSWs. Significant associations were found between treatment literacy and ART adherence and viral suppression, while positive patient-provider communication and respectful treatment were significantly associated with being virally suppressed. Cost of care was negatively associated with ART adherence and viral suppression. Peer navigation and support was found to positively enhance the quality of HIV services by promoting linkage and retention in care,

respectful treatment, greater access to comprehensive care, and contributing to increasing FSWs' agency in the clinic environment. Ultimately, peer navigation was linked to increased satisfaction with HIV services and was recommended by FSWs as a mechanism to improve HIV care among FSWs.

Findings from this study enhance the understanding of the context and association between HIV care and positive HIV outcomes, including ART adherence and viral suppression, among FSWs. Results highlight areas for programmatic investments to promote effective HIV treatment and care programs targeting key populations disproportionately affected by HIV.

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## Chapter 1: Introduction

Globally, female sex workers (FSWs) are among the most vulnerable populations that experience disproportionate burden of HIV.[1-10] These worldwide trends are reflected in the Dominican Republic (DR), where FSWs represent a highly marginalized group with nearly five times greater odds to be living with HIV compared to other adults (HIV prevalence of 4.4%[9] vs. 0.9%[11]). In the DR, interventions have focused on helping FSWs living with HIV navigate through the HIV care continuum.[8,9,12] However, despite evidence suggesting that FSWs are linking to HIV care and initiating ART treatment, HIV outcomes of ART adherence and viral suppression remain sub-optimal among this population.[8,9,12]

Research has shown the contributing role of the care environment on HIV outcomes. For example, positive perceptions of providers among FSWs could improve retention in HIV care,[13] while stigma and discrimination towards sex workers in healthcare settings could impact FSWs' access to formal healthcare services.[3,14-16] Furthermore, there is growing evidence suggesting that peer navigators can play an important role in helping vulnerable groups by assisting them in linkage and retention to HIV care and ART adherence[17,18] and may potentially serve as a means to improve the quality of treatment and care services among FSWs living with HIV.[8,9] Despite this evidence, there is a need for more in-depth exploration between the dynamics that shape the quality of treatment and care experiences of FSWs and the associations of these dynamics with HIV outcomes, specifically biological outcomes like viral suppression. Understanding the mechanisms through which the quality of HIV care affects HIV outcomes among FSWs, while exploring the role of peer navigation in shaping this relationship, provides an opportunity to generate evidence in support of effective programs and interventions aiming to support FSWs'

pathway towards viral suppression.

Given the disproportionate burden of HIV among FSWs in the DR, and the limited number of studies carefully exploring the relationship between quality of HIV care, peer navigation and HIV behavioral and biological outcomes, the proposed study integrates both qualitative and quantitative methods to assess this relationship. The study builds on a longitudinal, prospective cohort study being conducted in the DR, which includes a cohort of 211 FSWs living with HIV. The specific aims of the study are:

**Aim 1:** To explore the healthcare dynamics contributing to the quality of HIV care experienced by FSWs.

**Aim 2:** To examine the relationship between the quality of HIV care and HIV outcomes (ART adherence and viral suppression) among FSWs.

**Aim 3:** To describe the contributing role of peer navigation and support on the quality of HIV care experienced by FSWs.

Aim 1 was addressed through thematic analysis of two rounds of in-depth interviews (IDIs) (n=20, per round) exploring the experiences of FSWs in the HIV care environment. This analysis was complemented through clinic assessments (n=11) exploring the operations and resources of comprehensive HIV care facilities accessed by FSWs for their own HIV treatment and care. Taken together, the data from Aim 1 was used to explore the context of care and the dynamics that contribute to the quality of HIV care among FSWs. Results from Aim 1 helped inform the subsequent analysis for Aim 2. For Aim 2, we conducted a series of quantitative analyses of the

cross-sectional round 2 data from the parent study using random-effects multivariable logistic regressions. Through Aim 2, we explored if more positive experiences with quality of HIV care, as measured through provider and clinic related factors, were positively associated with self-reported ART adherence and achieving viral suppression. For Aim 3, we used both quantitative and qualitative methodologies. Drawing from survey data (n=211) and two rounds of IDIs (n=20 per round), we explored the experiences of FSWs with peer navigation and support, and the contributing role that peer navigation and support has in influencing the quality of their HIV care.

This research is embedded within the NIMH-funded parent study titled "Stigma, cohesion and HIV outcomes among vulnerable women across epidemic settings" (Grant #: R01MH110158; PI: Dr. Deanna Kerrigan). This longitudinal, prospective cohort study aims to establish the role of socio-structural and behavioral factors along the pathway to viral suppression among FSWs living with HIV to inform tailored and effective HIV prevention, treatment and care programs. The study is being conducted in two settings: Iringa, Tanzania and Santo Domingo, DR. In each setting, a cohort of approximately 200 FSWs living with HIV has been selected and is being followed prospectively.

The proposed study is expected to have an important contribution to the field of public health, as it will provide an in-depth assessment of the different components of quality of HIV care (i.e., clinic related and provider related factors) and how these affect the experiences of FSWs as they navigate through the HIV care continuum. Results from this study will contribute to the body of evidence on the clinic and provider level facilitators and barriers to achieving ART adherence

and viral suppression among FSWs. Furthermore, this study explores the potential influential role of peer navigation and support on the quality of HIV care. Understanding the role of peer navigation and support for FSWs in the HIV care continuum could contribute to the body of knowledge of effective intervention strategies among this population. Evidence generated by this study could also serve to improve programmatic activities and interventions geared towards FSWs and other key populations being disproportionately affected by HIV in order to improve their HIV outcomes and quality of life.

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## Chapter 2: Literature Review

### *The Epidemiology of HIV in the Caribbean and the Dominican Republic*

The Caribbean region has the second highest HIV prevalence in the world, only behind sub-Saharan Africa.[1,2] According to data from 2017, the HIV prevalence among adults ages 15-49 years in the Caribbean was approximately 1.2% with an estimated 310,000 people living with HIV (PLHIV) in the region.[2] Of these, 75% are currently living on the island of Hispaniola in Haiti or the Dominican Republic (DR).[3] In the DR, the HIV prevalence among adults ages 15-49 years was approximately 0.9% in 2017, with an HIV incident rate per 1,000 population of 0.38.[4] With regards to the HIV care continuum, lack of access to quality medical care services continues to hinder HIV treatment and care efforts in the DR.[3] For example, though 77% of PLHIV in the DR know their HIV status, only 52% report currently being on antiretroviral therapy (ART), and 43% are virally suppressed.[4]

In the DR, the HIV epidemic is concentrated among key populations, including female sex workers (FSWs), men who have sex with men (MSM) and transgender women.[2,3,5,6] These groups experience HIV vulnerability through many cultural, socio-economic and structural factors,[3,7-9] including poverty, gender inequality, persecution, and violence, among others.[3,10] In addition, misconceptions about HIV also continue to heighten the burden of HIV in the country by increasing stigma and discrimination towards PLHIV, MSM, and sex workers.[2,3]

***The Disproportionate Burden of HIV among FSWs: Globally, in the Caribbean and the DR***

Female sex workers (FSWs) are among the most marginalized populations that experience disproportionate risk of not only HIV/AIDS, but also experience a high risk of sexually transmitted infections (STI), stigmatization, discrimination and violence, among other human rights violations, that serves to elevate their susceptibility to HIV.[7,8,11-18] Globally, research suggests that FSWs continue to experience a heavy burden of HIV, with the majority of research reporting that FSWs are a high-risk group for infection.[19-23] The global HIV prevalence among FSWs continues to remain unacceptably high at 10.4%, with Latin American and the Caribbean having a combined estimated prevalence of 4.2%.[16] Evidence suggests substantially higher levels of HIV among FSWs compared to women of reproductive age across all geographic settings,[11,12,16,19-24] with research indicating that FSWs between the ages of 15 and 49 years having 13.5 times greater odds to be living with HIV compared to women of reproductive age overall in low- and middle-income countries.[19,25]

Despite its relatively small population size, the DR has a large number of women working as FSWs in diverse environments such as venue (e.g., discos, bars, and clubs) and non-venue based settings (e.g., street, cell-phones) with a report highlighting that there are between 60,000 to 100,000 FSWs in the country.[8,25] Global trends on the disproportionate burden of HIV among FSWs are reflected in the DR where FSWs have nearly 5 times greater odds to be living with HIV compared to other adults (HIV prevalence of 4.4%[8] vs. 0.9%[2]). The HIV prevalence among this group varies sharply across the country. For example, in Santo Domingo the estimated HIV prevalence was found to be 3.3% compared to 8.4% in the southwest city of Barahona where

prevention efforts targeting FSWs have been limited.[17] Stigma and discrimination are among the various social and structural factors influencing high rates of HIV among FSWs in the DR.[13,19,26] Other factors also influencing the heighten risk of HIV among FSWs in the country include mobility and migration, de facto criminalization of sex work as an occupation, violence and sex tourism.[3,10]

### *Understanding the social context placing FSWs at increased vulnerability to HIV and poor HIV outcomes*

Sex work continues to be one of the most contested occupations and/or activities globally,[27] with 116 countries subjecting sex workers to some form of legal prosecution, which places FSWs at an elevated risk for HIV.[25] In the DR, despite sex work not being subjected to punitive regulations or to criminalization,[2,28] FSWs experience significant stigma and discrimination often leading to fear of authorities and police prosecution.[7,28] A study by Carrasco and colleagues,[7] found that FSWs in the DR experience sexual violence by police and are often not afforded the same protection rights as other women. This prosecution or the criminalization of FSWs increases susceptibility to violence and further exclusion of FSWs in the policy agenda [29] as it contributes to the perpetration of society's negative views of FSWs on the basis of moral principles.[30] In fact, society continues to focus on socially constructed ideas of what it means to be a "good woman" and the notion of a woman involved in sex work continues to be one that is challenged in many parts of the world by many diverse and powerful groups, including, at times, feminist advocates.[31] Most importantly, criminalization of sex work hampers the ability of FSWs

to report client violence to authorities due to fear of prosecution or police retribution,[11] thus increasing their vulnerability of repeated client violence.

Research has also focused on investigating how violence against FSWs is a manifestation of the underlying sexual inequality between males and females, and the need for men (arguably a more dominant gender) to maintain this "unequal balance of power".[32] For example, in a qualitative study conducted in Kenya, the authors recognize that "gender-power differentials" along with "men's entitlement for sex sans money" unsurprisingly exposed FSWs to increased vulnerability to violence.[33] In this same study, female sex workers reflected that men's use of violence is a way to "humiliate," "dishonor" and "control" women who participate in sex work.[33] Given the contextual experiences and environment of FSWs, there has been a call, globally, for interventions and research to adopt multifaceted approaches that take into account the different socio-ecological spaces in order to explore socio-structural factors, such as violence, which undoubtedly contribute to exacerbate the burden of HIV among FSWs.[20,34-36] Understanding the contextual realities surrounding women who engage in sex work is imperative in order to not only understand the context that places them at heighten risk for HIV, but also this information serves to comprehend the reasons this population continues to experience sub-optimal HIV outcomes. For example, though behavioral campaigns focusing on increasing consistent condom use among FSWs have proven to be an effective strategic component to the fight against HIV transmission among this population,[10] research suggests that it is important to consider structural barriers, life-course vulnerabilities and other behavioral factors that may impede an intervention focusing on consistent condom use from being effective and thus continue to observe a disproportionate burden of HIV among FSWs.[17,37-39] To this end, research has shown that

gender-based violence (GBV) against FSWs is associated with increased vulnerability to HIV and STIs, and among FSWs living with HIV, it obstructs access to HIV treatment and care.[11,40,41] Furthermore, a meta-analysis found that among FSWs exposure to violence is rampant, with results indicating that the lifetime prevalence of work place violence ranged between 45% and 75%, while the lifetime prevalence of intimate partner violence ranged between 5% and 75%.[40]

Another factor contributing to the increase susceptibility of FSWs to HIV is substance use.[42-46] Given FSWs occupational environments, exposure to substances (including alcohol consumption and the use of illicit drugs) is common and many FSWs use drugs and alcohol, with studies suggesting that FSWs often report substance use as part of their work.[47-49] Heavy alcohol consumption often places FSWs at an increased risk for violence, sexual risk behavior, and HIV.[42,47,50] Similarly, it has been documented that FSWs' exposure to illicit substances, such as crack, is associated with risky sexual behavior and HIV infection.[51] Furthermore, among FSWs living with HIV, substance use has been associated with lower ART adherence, poor engagement in HIV care and detectable viral load.[17,52] For example, in the DR, use of drugs was associated with having a detectable viral load among FSWs living with HIV.[17] Furthermore, a study of FSWs who also engage in the use of illicit drugs, such as crack and heroin, found that among this sample there was a low rate of initiation of ART, engagement with HIV care and adherence to daily medication.[53]

Lastly, studies have signaled that among FSWs living with HIV, it is important to address how stigmas related both to their occupation and HIV status affect their HIV outcomes.[54-56] FSWs often exercise their occupation while experiencing feelings of blame and shame.[57] For example,

an exploratory study found that among FSWs, stigmatizing attitudes related to their occupation could lead to self-castigating beliefs in which women adopt stigmatizing viewpoints, such as believing their HIV status is a punishment due to their occupation.[7] These beliefs may in turn have a negative impact on HIV treatment and care outcomes such as engagement in HIV care and ART adherence. Evidence suggests that sex work related stigma and discrimination could prevent FSWs from accessing health services (e.g., by inhibiting HIV testing) and places women at increased vulnerability for violence, which indisputably positions FSWs at higher susceptibility to HIV/STI infections.[9,29,40,58] In addition, HIV related stigma has been found to be associated with decreased likelihood of ART uptake[59] and suboptimal ART adherence.[59,60] Research conducted in the DR has found that internalized sex work stigma among FSWs to be significantly associated with an increased odds of dropping out of HIV care and ART interruption.[61] Findings on the social vulnerabilities that place FSWs at an increased risk of HIV and poor HIV outcomes signal the need to understand the socio-cultural context of FSWs, especially as FSWs engage with HIV treatment and care services. Understanding these dynamics, which exacerbate sup-optimal HIV outcomes, could lead to more effective programing within HIV care facilities.

### *ART adherence and viral suppression among FSWs*

A growing focus has been placed on Treatment as Prevention (TasP), which aims to expand the use of ART as both a means to improve the individual health outcomes of PLHIV and to reduce the HIV incidence at the population level.[62,63] FSWs are among the key population groups for which approaches like TasP have been recommended given their elevated burden of HIV

compared to other adults and their important role in ongoing HIV transmission networks.[63,64] Nevertheless, FSWs highly stigmatized socio-cultural contexts has limited their access to healthcare and other social services thus creating a barrier for optimizing the use of ART among this population.[64,65] Globally, it is estimated that only 38% of FSWs have access to ART and among those 57% are virally suppressed.[63]

In the DR, interventions have focused on helping FSWs navigate through the HIV care continuum.[8,17,66] The HIV care continuum is defined as the steps ranging from HIV diagnosis, linkage to care, retention in care, ART adherence, and viral suppression.[67] Data from the *Abriendo Puertas* study in the DR found that among a cohort of nearly 250 FSWs living with HIV, FSWs were successfully obtaining their HIV diagnosis and linking to HIV care,[17] while program efforts were effective in increasing reported ART adherence.[8] However, viral suppression remained sub-optimal among this population, with only 51% of FSWs being virally suppressed post intervention efforts.[8] Another study conducted in the DR found similar results. This study found that despite results indicating a high rate of linkage to care and ART initiation, ART interruption continues to be frequent among FSWs with 36% of FSWs reporting having interrupted treatment at some point.[66] This study highlighted the effect that the healthcare system could have on FSWs ability to remained adherent to ART, with positive patient-provider relationship found as a protective factor against ART interruption.[66] These findings indicate the need to explore and address potential challenges in the quality of treatment and care services that may be contributing to FSWs' inability to remain adherent to ART and reach viral suppression, despite program efforts.

### *Quality of HIV care and HIV outcomes among FSWs*

In-depth exploration between the quality of treatment and care and HIV outcomes, specifically biological outcomes like viral suppression, has been limited among FSWs globally and in the DR. There is a need for greater information on how patient-provider dynamics and the clinic environment are associated with FSWs' HIV outcomes such as engagement in HIV care, ART adherence and viral suppression. Research has indicated that FSWs' interaction with healthcare professionals has an effect on how they navigate through the healthcare system. For example, stigma related to sex work inhibits FSWs' ability to speak about their occupation candidly with healthcare professionals and as a result may stop them from obtaining the comprehensive healthcare necessary for their protection against risk factors such as violence counseling, HIV/STI counseling, and the adoption of pre-exposure prophylaxis.[29,68,69] In addition, studies have shown that healthcare providers exhibit greater bias towards FSWs compared to those individuals living with HIV.[29] In fact, there is an independent (negative) association between sex work stigma and access to healthcare services.[13,29,35] A study by Nyblade and colleagues [56] found that healthcare workers engage in discrimination against sex workers at a high rate, with nearly 72% of FSWs in the study experiencing some form of sex work related stigma by healthcare providers.[56] This finding is alarming as it could effectively lead to the avoidance of health services among FSWs.[56] Similar findings were found in a qualitative study conducted in the DR and Swaziland where FSWs reported experiencing harsh treatment from clinical care providers not only due to their occupation, but also HIV status which often led to their avoidance of formal health services.[70] Furthermore, the clinic environment also shapes the experiences of FSWs as it relates to their HIV care. The same study by Kennedy and colleagues found that inability to have

medications on site or having to carry out laboratory analysis in other locations (i.e., outside of HIV care medical offices) as factors that hindered their HIV care experiences.[70] In fact, some participants in this study described navigating the healthcare system in the DR as time consuming, and such challenges could lead to poor treatment adherence.[70] In addition, other findings also suggest that retention in HIV care among FSWs is affected by negative experiences in the healthcare system.[61] These findings underscore the importance of HIV treatment and care services on FSWs' HIV outcomes. Though some evidence exists supporting this relationship, there is a need for a more in-depth assessment of the impact of quality of care (as measured through both provider and clinic level factors) on FSWs' HIV outcomes. In particular, there is a need for greater evidence describing the context of HIV care experienced by FSWs, to understand the dynamics that shape the quality of HIV care, and how these dynamics directly affect FSWs' pathway to viral suppression.

***Peer navigation as a critical component to improving the quality of HIV care***

Peer navigators have been used as part of a strategic approach to enhance PLHIV's engagement in care and ART adherence.[17,71,72] In the DR, a qualitative study found that MSM and FSWs highly support the use of peer counselors or health messengers as these individuals not only imparted instrumental knowledge about HIV and treatment, but also treat participants with respect.[70] As part of the *Abriendo Puertas* intervention conducted in the DR, peer navigators were established to bring forth support and accompaniment to FSWs living with HIV, while also advocating for them.[8,17] These peer navigators were women that could relate to the socio-cultural experiences of FSWs as they were involved in sex work, and understood the implications of

navigating the HIV care environment.[8,17] Though an in-depth examination was not conducted on the effect of peer navigators alone on FSWs' HIV outcomes, the overall *Abriendo Puertas* intervention –which included intervention components of (1) individual counseling, (2) peer navigation, (3) sensitivity trainings for clinicians and (4) community mobilization strategy– was found to improve ART adherence and consistent condom use among FSWs living with HIV.[8]

Findings from other settings and populations have also found the use of peer navigators to be instrumental in curtailing the HIV epidemic and improving the quality of life for PLHIV. For example, in South Africa, the use of peer navigators facilitated greater engagement in HIV care, ART adherence and enhance HIV prevention practices by helping participants overcome self-stigmatizing views on their HIV which often prevented them from accessing quality care.[71] This study also found that using individuals that could relate to patients through their lived experiences aids in fostering a trusting environment through rapport while providing patients with an example of how to model behavior to reach optimal HIV outcomes.[71] Another study conducted in the United States found that linking recently released inmates living with HIV to peer navigators was effective in preventing declines in viral suppression compared to inmates not linked to peer navigators (49% virally suppressed versus 30% virally suppressed).[72] Peer navigators in this study were also selected based on their ability to relate to recently released inmates not only on the basis of HIV status and incarceration experience, but also on race/ethnicity and sexual identity.[72]

Despite existing evidence on peer navigation as a critical strategy for improving HIV outcomes, there is limited research on understanding the mechanisms through which peer navigation shapes

the quality of the HIV care experienced by FSWs. In the DR, peer navigation for FSWs continues to operate in different healthcare environments, exploring the effect of peer navigators on FSWs' HIV care experience provides an opportunity to enhance our understanding on the instrumental role that peer navigation may have in aiding FSWs to successfully navigate through the HIV care continuum and achieve favorable HIV outcomes.

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## Chapter 3: Theory and Conceptual Framework

The conceptual model displayed in **Figure 3-1** provides a graphical description of the role and potential pathways by which quality of HIV care may influence ART adherence and viral suppression among FSWs. In addition, the model provides a graphical description of the potential role of peer navigation and support on the quality of HIV care, the relationship between quality of HIV care and HIV outcomes, and agency.

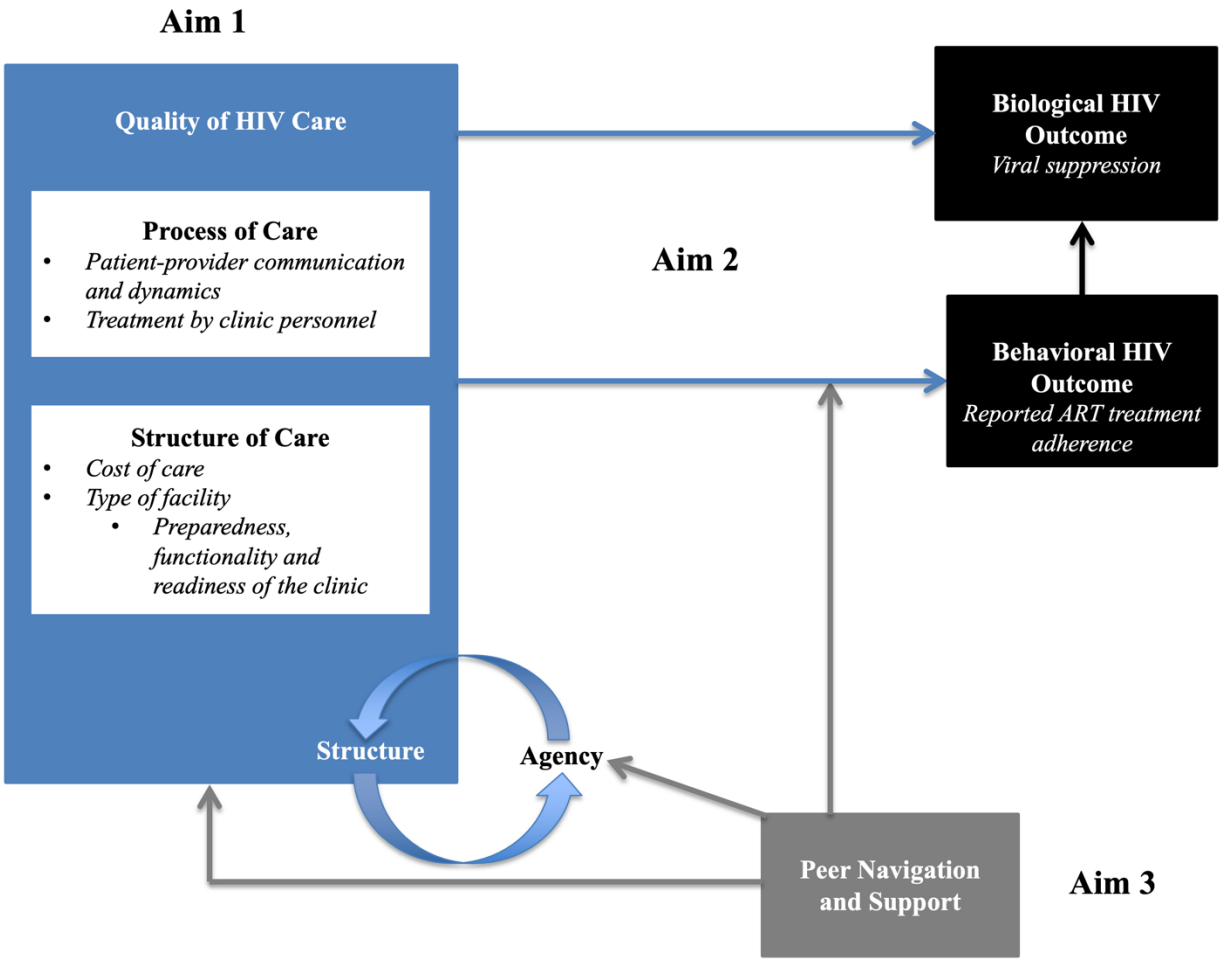


**Figure 3-1.** Conceptual model linking quality of HIV care and peer navigation to HIV outcomes

The conceptual model is influenced by the Donabedian framework on quality assurance in health care to understand how quality of care affects HIV outcomes.[1] In his previous work, Donabedian acknowledges that quality of care is a "remarkable difficult notion to define"[2] given the different attributes or elements in the care process that investigators find important when it comes to assessing the quality of care received and its effect on society at large.[1,2] Nevertheless, under Donabedian's framework there is a recognition that there are key elements that drive the type of care that healthcare structures render to their patients. These elements or criteria fall under the concept of acceptability of care or the degree to which the care received conforms to the "wishes, desires, and expectations" of patients and their caretakers.[1] There are key elements in the care routine that could contribute to acceptability including, equity in care, patient preferences for care which incorporates views on cost of care, amenities of care, the patient-provider relationship, and access to care.[1] Through this lens, the Donabedian framework defines the effect that quality of care may have on outcomes as the effect of *structure of care* measures - defined as the conditions under which care is rendered to patients - and the *process of care* measures – defined as the activities that constitute the receipt of care including interpersonal relationships between patient and providers. This has come to be defined as Donabedian's Structure-Process-Outcome Model.[1] Based on this conceptualization, we posit that *process of care* elements under this domain are relational and could include patient-provider communication and dynamics, and treatment in the clinic environment. *Structures of care* elements include the aspects more directly related to the health care structure and could include cost of care, and the type of facility- taking into consideration preparedness, functionality and readiness of the facility to provide the needed HIV care to patients.

The proposed study's conceptual model also draws from Freire's theory of critical consciousness[3,4] to understand the effect that peer navigation and support may have on the quality of HIV care, and on the pathway to reaching positive HIV outcomes. Freire's theory on critical consciousness argues that people are often not aware of structural inequalities and as such cannot take the appropriate steps to combat oppressive systems that continue to perpetuate their inequality.[3-5] Freire argued that it is important for people experiencing inequality due to oppressive norms and structures to "think critically about oppressive realities and challenge inequitable social conditions to reclaim their humanity."[5] One method of achieving this is by generating a space for critical consciousness to grow through practices wherein people could become aware of their inequality through community empowerment strategies, such as the use of community health workers or peer navigators.[6,7]

Among FSWs living with HIV, FSWs are exposed to a socio-cultural environment, which often limits their ability to navigate through often complex and fragmented healthcare structures.[8] FSWs often experience stigma and discrimination from the community and healthcare professionals,[9] in addition, to experiencing their own self-stigmatizing views, which is often inundated with feelings of shame.[10] Peer navigators could be an instrument for combating these experiences and addressing the healthcare barriers that lead to suboptimal HIV outcomes among this population. Previous work has used a Freirean lens of critical consciousness to explore the implications of community health workers (or *promotores* in Spanish) in reducing health disparities among key populations such as Latinos living in the United States.[6,11] Community health workers are typically members from the community and as such could aid in serving their community by promoting positive health by introducing interventions or programs that are both

culturally and linguistically appropriate, while also advocating and in turn challenging systems to bring forth more equitable opportunities for the community. Through these actions, community health workers are able to create a space where critical consciousness could propagate, and as a result, communities become aware and subsequently begin to address the most pressing issues affecting their health while challenging the barriers inhibiting their health promotion efforts. These principles are guiding the conceptual model in understanding the effect that peer navigation and support may have on influencing the pathway from quality of HIV care to ART adherence and viral suppression. In our study, peer navigation is performed by current or former FSWs who have experience with HIV outreach, prevention, and support activities for people living with HIV.[12,13] As such, the model postulates that given peer navigators ability to provide culturally and linguistically appropriate assistance and support to FSWs living with HIV, and to help challenge structural barriers, peer navigation could play an influential role in the HIV care experiences of FSWs and their HIV outcomes.

Lastly, the proposed study also drew from Gidden's Structuration Theory to understand how individual level factors could also influence the quality of HV care received by FSWs. Gidden's Structuration Theory aptly affirms the value that a person's own agency, or sense of power, has on their ability to affect their outcomes.[14] As such, the proposed study acknowledges the potential role of agency, for example through patients' own treatment literacy and actions taken through their own treatment literacy, and the contribution it may have in understanding the quality of HIV care dynamics that contribute to HIV outcomes. In addition, the proposed study acknowledges that through peer navigation and support, FSWs could build or strengthen their

agency or sense of power to make decisions directly affecting their own experiences with HIV treatment and care.

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## Chapter 4: Research Design and Methods

### Research Aims, Hypotheses and Summary of Methods

The study utilized quantitative data of 211 HIV-infected FSWs from Santo Domingo, DR, while also drawing from data from a qualitative subsample (n=20) and clinic assessments (n=11). The specific aims of the proposed study included:

**Aim 1:** To explore the healthcare dynamics contributing to the quality of HIV care experienced by FSWs.

*Methods*

Aim 1 was addressed through data from a qualitative subsample of FSWs (n=20) who completed two rounds of semi-structured, in-depth interviews as part of the parent study. Interviews explored a series of topics including: (1) Participants' perceptions of their current HIV care; (2) Participants' understanding of their current HIV treatment; (3) Facilitators and barriers to receiving HIV treatment and care; and (4) Recommendations to improve their HIV treatment and care experiences. Qualitative data was complemented through a clinic assessment (n=11) conducted in both public and private facilities exploring the spaces, resources and operations of HIV clinical sites.

**Aim 2:** To examine the relationship between the quality of HIV care and HIV outcomes (ART adherence and viral suppression) among FSWs.

*Hypotheses*

More positive experiences with quality of HIV care, as measured through provider and clinic related factors, will be:

2.1: positively associated with self-reported ART adherence

2.2: positively associated with achieving viral suppression

*Methods*

Aim 2 was addressed through quantitative analyses of cross-sectional round 2 data from the parent study (n=211) using multivariable logistic regressions.

**Aim 3:** To describe the contributing role of peer navigation and support on the quality of HIV care experienced by FSWs.

*Hypotheses*

Peer navigation is associated with positive HIV care experiences. In particular, peer navigation will be:

3.1: positively associated with improving positive treatment by clinical care providers

3.2: positively associated with enhancing patient-provider communication

3.3: positively associated with greater satisfaction with overall HIV care

*Methods*

Aim 3 was addressed through quantitative analyses of cross-sectional round 2 data from the parent study (n=211) through the use multivariable logistic regressions. Addressing this aim was

further enhanced by data from a qualitative subsample of FSWs (n=20) who completed two rounds of semi-structured, in-depth interviews as part of the parent study, focusing on exploring experiences of FSWs with peer navigation and support in HIV care.

***Parent Study***

The proposed study is embedded within the NIMH-funded parent study "Stigma, cohesion and HIV outcomes among vulnerable women across epidemic settings" (Grant #: R01MH110158; PI: Dr. Deanna Kerrigan), which is a longitudinal observational cohort study being conducted in Iringa, Tanzania and Santo Domingo, DR. The study aims to establish the role of socio-structural and behavioral factors along the pathway to viral suppression among FSWs living with HIV to inform tailored and effective HIV prevention, treatment and care programs. In each of these two settings, a cohort of approximately 200 FSWs living with HIV has been selected and is being followed prospectively at 0, 12 and 24 months.

As part of the parent study, a subsample of 40 women (n=20 in Tanzania and n=20 in the DR) from the original cohort were invited to form part of a qualitative longitudinal cohort study aiming to explore the dynamic context of social cohesion and HIV and sex work related stigma among FSWs in relation to HIV services and outcomes. This qualitative cohort is being followed prospectively and will complete a total of three rounds of semi-structured, in-depth interviews (IDIs), with each interview being conducted annually since October 2018.

Clinic assessments of public and private HIV care facilities (n=3 in Tanzania and n=11 in the DR) were also completed to support the data collection strategies of the parent study. Informed

by the quantitative survey data in each setting, information on participants' regularly visited HIV care facility was collected at the baseline (at 0 months) of the parent study. This information was used to establish a list of HIV care facilities serving as the sample for the clinic assessment. The clinic assessment assessed the clinic environment and explored the dynamics and operations influencing the delivery of HIV treatment and care.

The current research utilized round 2 (at 12 months) survey data along with data from the qualitative subsample and the clinic assessment from the DR cohort of the parent study to address Aims 1, 2 and 3.

***Study Population and Recruitment***

The DR cohort was based largely on an already established longitudinal cohort of FSWs living with HIV through the support of a PEPFAR/USAID funded study "Examining the feasibility and initial effects of an integrated HIV prevention and care intervention among Female Sex Workers living with HIV and their male regular partners"[1,2] (Grant #: GHH-I-02-07-00032-00; PI: Dr. Deanna Kerrigan). Recruitment of study participants was further enhanced through the aid of peer navigators from the sex worker-rights group, MODEMU (*Movimiento de Mujeres Unidas*), key informants, and participants themselves. Eligibility criteria for participants in the parent study included being at least 18 years of age, with a confirmed HIV-positive diagnosis utilizing a rapid test (Retrocheck from Qualpro Diagnostics) and having reported exchanging sex for money in the last month prior to enrollment. Women who did not meet the eligibility criteria or were unable to provide informed consent were excluded from the parent study. Women recruited for

the study completed a socio-behavioral survey, along with clinical laboratory tests (i.e., testing for presence of antiretroviral drugs, resistant strains of HIV and viral load). In addition, as part of the parent study, review of medical charts for all participants in the study was conducted.

*Qualitative subsample.* Participants for the qualitative subsample were recruited using a stratified purposeful sampling approach,[3] sampling participants based on viral suppression at baseline (at 0 months). This approach resulted in the formation of a longitudinal cohort of 20 participants comprised of 10 virally suppressed (less than 400 copies/mL) and 10 not virally suppressed (400 or more copies/mL).

*Clinic Assessment.* A total of 11 HIV comprehensive care centers in the Dominican Republic, 7 public and 4 private facilities, were part of the clinic assessment. Facilities for the clinic assessment were chosen through the use of survey data wherein participants were asked to provide information on the HIV medical care facility where they receive their own HIV care. This information was also supplemented through the medical chart review.

***Data Collection Procedures***

The current study uses data from the second round of data collection (at 12 months) in the DR (n=211) collected between December 2018 and November 2019. Data collection was conducted by the IDCP (*Instituto Dermatológico y Cirugía de Piel Dr. Huberto Bogaert Díaz*) in Santo Domingo, DR. Surveys were administered by experienced interviewers utilizing a tablet in a private location at a time most convenient for study participants. Prior to administering the

survey, interviewers collected informed consent from each participant, and for participants with a non-confirmed HIV diagnosis, a rapid test was administered to confirm HIV status. The survey examined a range of topics, including: demographic and occupational characteristics, experience with HIV and sex work related stigma, provider communication and dynamics, satisfaction with clinic and HIV related services, experience with peer navigation, experience with ART stigma and ART adherence. During each survey visit, participants who provided informed consent also participated in a blood draw (of 10 mL) done by the IDCP laboratory team. The IDCP laboratory team then used the 10 mL of blood to create three 1.8 mL plasma aliquots, which were then stored at -80$^{o}$C and shipped using the appropriate laboratory procedures. For viral load, the testing took place at the National Dominican Reference Laboratory. HIV viral load testing was assessed using polymerase chain reaction (PCR) technology with the Roche Amplicor HIV-1 Monitor Test. In addition, supported by informed consent, a medical chart review was also conducted for all participants enrolled in the parent study. All participants in the parent study received 400 Dominican pesos (approximately $7 US Dollars) compensation for their time during each study visit.

*Qualitative subsample.* The current study uses data from the first two round of semi-structured, in-depth interviews (IDIs) conducted with the qualitative subsample from the parent study. All IDIs were conducted in Spanish by two trained interviewers in a private office at the IDCP after securing informed consent from all participants. All 20 participants completed the first round of IDIs between October and November 2018, while 18 participants completed the second round of IDIs between December 2019 and January 2020. **Table 4-1** presents an example of the questions included in the semi-structured, IDI guides. IDIs included questions related to: (1) Participants'

perceptions of their current HIV care; (2) Participants' understanding of their current HIV treatment; (3) Facilitators and barriers to receiving HIV treatment and care; and (4) Recommendations to improve their HIV treatment and care experiences. Each IDI lasted approximately 60 minutes, and participants received 400 Dominican pesos (approximately $7 US Dollars) compensation for their time during each interview.

**Table 4-1.** Example of questions included in the semi-structured, in-depth interview guides

| Topic | Sample Questions |
|---|---|
| **Linkage to HIV care** | • How long has it been since you were diagnosed with your first visit to a doctor (or medical professional) for medical care and treatment for HIV?<br>• Tell me about the process of going to a clinic and beginning to receive HIV care and treatment. |
| **Current HIV care experiences** | • How are you doing with HIV-related care?<br>• Where do you go to get your antiretrovirals (ARVs), that is, medicines for HIV?<br>• Tell me about your appointments at the clinic. From when you arrive until you leave, what are all the things you do?<br>• How often do you go to the clinic for HIV care? |
| **Recommendations for improving HIV care experience** | • What would help you improve your overall experience with HIV care and treatment?<br>• What programs do you think would help you? |

*Clinic Assessment.* The current study draws from clinic assessment data from the parent study. Trained interviewers conducted clinic assessments via direct observations of the clinic spaces and facilities, and through close-ended questions administered to clinic staff and HIV care providers. Data collection for the clinic assessment was completed between March and July 2019.

**Table 4-2** presents a sample of the questions included in the clinic assessment. The clinic assessment focused on understanding the dynamics and operations of HIV facilities. Measures on the preparedness, functionality and readiness of the clinic were influenced by the observation

manual used in Brazil to examine the quality of outpatient care in public services for PLHIV known as Qualiaids.[4] The assessment explored provider composition, typical wait time for HIV care appointment and medication refill, and typical length of initial and follow-up HIV medical consultations. In addition, the assessment also explored the capacity of the clinic to provide ART to patients (i.e., ART stock) and conduct laboratory assessments of viral load and CD4 tests. Furthermore, the clinic assessment explored other services, beyond HIV care, provided on site. All of these variables were used to investigate the HIV care context and clinics' preparedness, functionality and readiness to provide HIV attention and care to participants.

**Table 4-2.** Example of questions included in the clinic assessment

| Sample Question | Variable Type | Operationalization |
|---|---|---|
| How many healthcare providers are treating people with HIV in the facility? | Continuous | |
| Do you currently have a supply of antiretroviral drugs (ARVs) at your facility? | Dichotomous | 0= No<br>1= Yes |
| In the past 12 months, in how many months were there not enough ARVs for all patients? | Continuous | |
| Is there a functional and currently working CD4 (and viral load) machine on site? | Dichotomous | 0= No<br>1= Yes |
| Describe the environment of the clinic:<br>1. Consultation offices<br>2. Waiting room spaces<br>3. Bathroom facilities<br>4. Overall clinic environment | Open-ended | |

***Quantitative Measures***

<u>Aim 2</u>

**Table 4-3** provides a sample list of the measures of interest for Aim 2 of the current study drawing from the quantitative survey.

*HIV outcome measures.* Self-reported ART adherence was measured by investigating participants ART adherence over the past 4 days. In particular, participants were asked on how many days, during the past 4 days, they have missed taking their ART medication, with answers for this question ranging from none to 4 days. Responses for this question were dichotomized with "0" indicating no ART adherence in the last 4 days, and "1" indicating adherence to ART in the last 4 days. The measure of viral suppression was created based on participant's viral load. Participants with less than 400 copies/mL were coded as being virally suppressed, while participants with viral loads of 400 or more copies/mL were classified as not being virally suppressed.

*Individual measures.* Participants' *treatment literacy* was assessed through two questions inquiring about viral load and CD4 count and how these two biological measures relate to their HIV treatment. Participants were asked if the goal of treatment is to make viral load go up or down, and if the goal of treatment is to make the CD4 count go up or down. Participants who responded correctly to viral load (the goal of treatment is to make viral load go down) were coded as having an understanding of viral load as it relates to their treatment plan. Participants who responded correctly to CD4 count (the goal of treatment is to make CD4 count go up) were coded as having an understanding of CD4 count as it relates to their treatment plan. Other individual level characteristics included participants' age and educational attainment.

*Process of care measures.* Sex work disclosure to healthcare providers was assessed through a question in which participants are asked if their healthcare provider has asked about their sex work occupation, answers for this question were captured as yes or no. Patient-provider communication and trust was assessed through Galassi's 15-item validated scale on Patient Reactions Assessment (PRA).[5] PRA provides a measure for the perceived quality of the information given by the provider, affective behaviors of the provider, and patient's perceived ability to communicate with the provider.[5] Cronbach's alpha was used to assessed the internal consistency, or reliability, with a value of 0.80 or higher indicating that the scale has good internal consistency.[6,7] The PRA scale has been used in previous studies working with FSWs living with HIV in the DR,[8,9] and was found to have a good reliability with a Cronbach's alpha of 0.80. Continuity of care was assessed through a survey question asking participants if they are seen by the same provider during each HIV care visit. Treatment by clinic staff was measured using a survey item assessing patient interaction with clinic staff. This item measured feeling respected by clinic staff with answers on an ordinal scale ranging from 1=always to 4=rarely or never. This measure was dichotomized to indicate always being respected versus not always feeling respected by clinic staff.

*Structure of care measures.* Based on survey responses to questions about location where participants obtain their HIV care, and confirmed through medical chart review, we developed a variable on type of medical facility where the participant receives care, with options of care facility being either a public or private HIV comprehensive care service site. Cost of care was developed utilizing an index of different type of items associated with HIV care costs. These items included any payments or fees made as part of the HIV care visit, any additional

medication costs incurred during the HIV care visit (this item excluded ART costs as ART is provided free of charge in the DR[10]), any costs associated with transportation to clinic appointments, any costs associated with food intake during the HIV care visit, any costs associated with childcare incurred due to the HIV care visit, and any loss of income due to the HIV care visit. These associated HIV care costs were totaled and split around the median for the purpose of analysis.

*Other covariates.* In our model, we also controlled for socio-demographic characteristics including age, education, and currently living with a partner.

**Table 4-3.** Description and operationalization of variables of interest for Aim 2

| Variable | Method of Measurement | Sample Question | Time Frame | Variable Type | Operationalization |
|---|---|---|---|---|---|
| **Outcome Variables** | | | | | |
| Behavioral reporting of ART treatment adherence | Survey question | During the past 4 days, on how many days have you missed taking all your doses of Antiretroviral Therapy (ART) i.e., medicines to fight HIV? | 4 days | Categorical | 1= None<br>2= One day<br>3= Two days<br>4= Three days<br>5= Four days<br>6= Don't remember |
| Viral suppression | Laboratory test | N/A | N/A | Dichotomous | 0= Not virally suppressed<br>1= Virally suppressed |
| **Individual Measures** | | | | | |
| Treatment Literacy | Survey question | Is the goal of treatment to make the CD4 count go up or down? | N/A | Dichotomous | 0=Down<br>1=Up |
| Treatment Literacy | Survey question | Is the goal of treatment to make the viral load go up or down? | N/A | Dichotomous | 0=Up<br>1=Down |
| **Process of Care Measures** | | | | | |
| Patient-provider communication and dynamic | Survey question: Based on Galassi's 15-item Patient Reactions | When I talk to my HIV provider, it is difficult to get conflicting information straightened out. | N/A | Continuous | 1= Strongly disagree<br>2= Disagree<br>3= Agree<br>4= Strongly agree |

| Variable | Method of Measurement | Sample Question | Time Frame | Variable Type | Operationalization |
|---|---|---|---|---|---|
| | Assessment (PRA) | | | | |
| Disclosure of sex work to provider | Survey question | Has a health care worker ever asked you if you exchange sex for money? | N/A | Dichotomous | 0=No<br>1=Yes |
| Continuity of care | Survey question | Do you see the same provider(s) every time you visit the clinic where you get your HIV care? | N/A | Dichotomous | 0=No<br>1=Yes |
| Treatment by clinic staff | Survey question | The staff at the clinic where you get your HIV care treats you with respect… | N/A | Categorical | 1= Always<br>2= Most of the time<br>3= Some of the time<br>4= Rarely or never<br>5= Doesn't know<br>6= Has never received HIV care |
| **Structure of Care Measures** | | | | | |
| Cost of Care | Composite measure created from 12 variables assessing associated costs of HIV care visit | How much money does it cost to travel to and from this clinic (round-trip) for your HIV appointment? | N/A | Continuous | |
| Type of Facility | Medical chart review and Survey question | Type of HIV care facility | N/A | Dichotomous | 1=Private<br>2=Public |

Aim 3

**Table 4-4** provides a sample list of the measures of interest for Aim 3 of the current study drawing from the quantitative survey.

*Relational Aspects of Quality of Care.* The survey was used to obtain two of the main outcomes of interest: patient-provider communication and respectful treatment by clinic staff in the HIV care environment. These outcome variables have been described in the section above ("Aim 2 Process of Care Measures").

*Overall Satisfaction with HIV Care Services.* The last outcome of interest is overall satisfaction with HIV clinic services. Overall satisfaction with HIV care was assessed through a question inquiring participants' rating of the services at the clinic where they receive their HIV care, with answers ranging from 1=excellent to 5=weak. This variable was dichotomized to indicate a rating of very good or excellent versus not very good or excellent. This measure on clinic satisfaction has been tested in this context (i.e., FSWs living with HIV in the DR) as part of the *Abriendo Puertas* program evaluation.[8]

*Peer Navigation.* The main independent variable of interest, peer navigation, was assessed utilizing 8 survey items, which have been previously included as part of the *Abriendo Puertas* intervention evaluation in the DR.[1,2] Participants were asked to report the level of engagement with peer navigators (including if they have had contact with peer navigators and frequency of contact). In addition, participants were also asked if peer navigators have provided accompaniment to HIV care appointments and other types of appointments outside of HIV care. Based on this information, we constructed a dichotomous measure to indicate whether or not participants have had any contact with a peer navigator in the past 6 months. Other variables related to peer navigation were used to provide a more nuanced description of the type and level of engagement participants reported having with a peer navigator.

*Other covariates.* In our model, we controlled for socio-demographic characteristics including age, education, currently living with a partner, and years living with HIV.

**Table 4-4.** Description and operationalization of variables of interest for Aim 3

| Variable | Method of Measurement | Sample Question | Time Frame | Variable Type | Operationalization |
|---|---|---|---|---|---|
| **Outcome Variables: Relational Aspects of Quality of Care and Overall Satisfaction with HIV Care** | | | | | |
| Treatment by clinic staff | Survey question | The staff at the clinic where you get your HIV care treats you with respect… | N/A | Categorical | 1= Always<br>2= Most of the time<br>3= Some of the time<br>4= Rarely or never<br>5= Doesn't know<br>6= Has never received HIV care |
| Patient-provider communication and dynamic | Survey question: Based on Galassi's 15-item Patient Reactions Assessment (PRA) | When I talk to my HIV provider, it is difficult to get conflicting information straightened out. | N/A | Continuous | 1= Strongly disagree<br>2= Disagree<br>3= Agree<br>4= Strongly agree |
| Clinic Satisfaction | Survey question | Overall, the services at the clinic where you get your HIV care are: | N/A | Categorical | 1= Excellent<br>2= Very good<br>3= Good<br>4= Adequate<br>5= Weak<br>-97= Doesn't know |
| **Peer Navigation Measures** | | | | | |
| Exposure to peer navigation | Composite aggregate measure developed from a series of 8 questions | Have you had contact with a peer navigator about HIV/AIDS? | 6 months | Categorical | Composite score made up of 4 categories:<br>0=No exposure to peer navigation<br>1=little exposure to peer navigation<br>2=Moderate exposure to peer navigation<br>3=High exposure to peer navigation |

***Power Calculations and Sample Size***

Aims 1 and 3

For Aims 1 and 3, the current study uses data from the first two rounds of semi-structured, IDIs completed with the qualitative subsample of FSWs (n=20 in round 1 and n=18 in round 2). Saturation was used as a means of evaluating the sample size for the current study. Saturation has been established as one of the standards to establish rigor in qualitative studies, which use non-probabilistic sampling.[11,12] Though the estimated sample size to reach saturation varies, evidence suggests that for purposeful sampling, thematic saturation could be reached at 12 interviews.[11] Nevertheless, another study found that sampling for saturation in qualitative studies varies and it is dependent on what the study aims to achieve.[12] Hennink and colleagues describe two types of saturation: coding saturation and meaning saturation. Coding saturation relates to the concept that no new information is being captured through the use of codes or the idea that everything has been heard.[12] Meaning saturation relates to the concept that no new information is emerging to aid in the understanding of the phenomenon of interest.[12] According to Hennink and colleagues coding saturation is reached at about 9 interviews, whereas it takes 16 to 24 interviews to reach meaning saturation. The current study prioritized meaning saturation over coding saturation, while keeping in mind study feasibility. As such, a sample size of 20 FSWs, with most completing two rounds of IDIs, was found to be sufficient to reach meaning saturation and ensure rigor related to the qualitative methods utilized to understand perceptions and experiences surrounding the dynamics that contribute to the quality of HIV care, and the role of peer navigation and support in FSWs' HIV care experiences.

Aim 2

The main outcome of the current study is to determine how quality of HIV care affects HIV outcomes among FSWs. To determine the study power needed to detect a difference in the main HIV outcomes (ART adherence and viral suppression), a set of parameters was established using the previous data on FSWs living in the DR from the *Abriendo Puertas* study, and back calculations of power for the proposed analysis were performed. Furthermore, the main outcome of the proposed study (Aim 2) was used to perform these calculations. In addition, given the evidence on the critical role that providers have on quality of treatment and care among FSWs living with HIV in the DR,[8,9] power calculations utilized the independent measure of level of positive perceptions with HIV providers based on Galassi's PRA scale.[5] The statistical power calculations followed the following assumptions: (1) there is a total of 201 FSWs living with HIV in the cohort (based on baseline data given that power calculations were conducted prior to the completion of round 2 data collection); (2) there is an estimated prevalence of high level of positive perceptions with HIV providers of 47.06% (based on unpublished *Abriendo Puertas* data); (3) the base rate of ART adherence among FSWs in the DR is 72.47%;[1,2] and (4) the base rate of undetectable viral load among FSWs in the DR is 49.78%.[1,2] Furthermore, analysis of the *Abriendo Puertas* baseline data revealed that among FSWs who report high levels of positive perceptions with HIV providers, 78.45% reported being adherent to their ART medication; whereas, among FSWs who report medium to low levels of positive perceptions with HIV providers 69.70% reported being adherent to their ART medication. Using this information, the back calculations of power suggest that there is sufficient information to detect 80% power and established significant differences on the primary outcomes of interest, ART adherence and viral

suppression, between FSWs who report high level (89% of ART adherence and 70% of viral suppression) versus medium/low levels (72% ART adherence and 50% of viral suppression) of positive perceptions with HIV care providers (**Table 4-5**). Furthermore, evidence suggest that the inclusion of highly correlated indicators or measures (multicollinearity) as well as unnecessary adjustment of covariates could dilute the precision of logistic regression models,[13,14] as such, the current study closely investigated the covariates being included in the models in order to ensure that model precision and power is not diluted; as such, allowing for the testing of the main study aim.

**Table 4-5.** Study power to detect differences in ART adherence and detectable viral load among a cohort of 201 FSWs living with HIV in the DR

| Outcome of Interest | High level of positive perceptions of HIV care providers | Medium to low levels of positive perceptions of HIV care providers | Difference | Alpha | Power |
|---|---|---|---|---|---|
| ART Adherence | 89.02% | 69.70% | 0.1932 | 0.05 | 0.9287 |
| | 89.02% | 72.00% | 0.1702 | 0.05 | 0.8669 |
| | 89.02% | 75.00% | 0.1402 | 0.05 | 0.7383 |
| Undetectable viral load | 69.78% | 49.78% | 0.2000 | 0.05 | 0.8293 |
| | 66.78% | 49.78% | 0.1700 | 0.05 | 0.6884 |
| | 63.78% | 49.78% | 0.1400 | 0.05 | 0.5175 |

***Data Analysis***

Aim 1

Aim 1 utilized two rounds of data from the qualitative subsample (n=20 in the first round and n=18 in the second round) collected through the parent study, while also incorporating data collected from clinic assessments (n=11). All interviews were transcribed and analyzed in Spanish. Data analysis focused on the questions surrounding experiences with HIV care. In

particular, the Student Investigator was interested in questions related to: (1) Participants' perceptions of their current HIV care; (2) Participants' understanding of their current HIV treatment; (3) Facilitators and barriers to receiving HIV treatment and care; and (4) Recommendations to improve their HIV treatment and care experiences. The Student Investigator relied on an iterative analytical approach using thematic analyses to allow for a deeper analytical exploration of the data within and across participants. First, each transcribed interview was read thoroughly prior to coding to allow for a deeper immersion into the contextual realities of each participant. This exercise allowed the Student Investigator to begin thinking about the development of codes, while also keeping in mind the nature of the interviews. In addition, a select number of interviews were read while listening to the audio recordings in an effort to assess the quality and accuracy of the transcriptions. Next, interviews were analyzed using a thematic analysis approach[15] applying a combination of both inductive and deductive techniques. Analysis began with a set of a priori topics or codes, while embarking on a deeper exploration by building on the data itself and allowing the emergence of new topics or codes. Throughout the coding and overall analytic processes, coding memos were used to describe changes to the methodology, begin to synthesize the data, and capture any relevant thoughts that could have implications in the conceptualization of results. Research debrief meetings with the study team were conducted to assess the dependability and confirmability of the results by engaging in rich discussions to explore all of the results in detail.[16] Atlas.ti version 8.4.4[17] was used to managed the qualitative data.

The assessment of the clinic level data was based on descriptive statistics of the quantitative data. The Student Investigator explored overall frequencies and proportions of the total sample (n=11),

while also observing any commonalities or differences between the clinics by type of facility (public versus private). Interviewers' clinic qualitative observations were explored by the Student Investigator and used to refine quantitative findings and provide a fuller description of the clinic environment. All data was explored in Spanish utilizing Stata SE version 15.1.[18]

Aim 2

The analysis of Aim 2 built on the work conducted through the analysis of Aim 1. Aim 1 provided an understanding for the potential quality of HIV care dynamics that may be influencing ART adherence and viral suppression among FSWs. Aim 2 relied on the second round of data collected (n=211) through the parent study via the socio-behavioral survey and biological assessments. The Student Investigator first began to explore the data from round two by conducting exploratory data analysis on key variables of the survey data. Specifically, the distributions of continuous variables were examined noting particular parameters such as the mean, median, standard deviation, interquartile range (IQR) and range. Categorical variables were assessed through the use of frequencies and proportions. Visual descriptions (not shown) of the variables were examined through the use of histograms and box-plots in an effort to understand the distribution of the different measures. Associations between the two HIV outcomes of interest, ART adherence and viral suppression, was explored through a Chi-Squares test and a simple logistic regression. Regarding model selection, variables included in the model were selected informed by the qualitative data analysis on the most pertinent measures that affect the dynamics of quality of HIV care among FSWs (based on results from Aim 1). As such, the model was built under the hypothesis that both measures of process of care and structure of care,

along with individual measures that examine agency via treatment literacy, would be associated with ART adherence and viral suppression. For each outcome, we explored these associations utilizing a random-effects multivariable logistic regression in order to account for potential intra-cluster correlations among FSWs who access HIV care from the same HIV care facility. A total of 11 different public and private clinics were documented for our sample. Results from these random-effects multivariable logistic regressions are expressed in terms of adjusted odds ratio (AOR) and 95% confidence intervals (CI). The Student Investigator also imputed data on 18 observations collected during round two that had missing information on select questions assessing their clinic level care utilizing participant data from round one. Sensitivity analyses indicated that the models presented as part of the results were not affected by these imputations, as results changed only marginally and the main conclusions of the study hold. All analyses were conducted using the quantitative software Stata SE version 15.1.[18]

Aim 3

Aim 3 relied on the second round of data collected (n=211) through the parent study via the socio-behavioral survey and biological assessments, while further complementing this data with the two rounds of data from the qualitative subsample (n=20 in the first round and n=18 in the second round). Aim 3 built on findings from Aim 2 by seeking to understand how the relational aspects of quality of care may be influenced by the role of peer navigation and support. Similar to Aim 2, the Student Investigator first began exploring the quantitative data from the round two survey by conducting exploratory data analysis on outcomes of interest, relational factors of quality of care and satisfaction with HIV care, and peer navigation measures. Other socio-

demographic, occupational, and HIV related variables were also explored as part of the analysis. Distributions of continuous variables were assessed noting particular parameters such as the mean, median, standard deviation, interquartile range (IQR) and range, while categorical variables were assessed through the use of frequencies and proportions. Associations between the outcomes of interest, patient-provider communication, respectful treatment in HIV care environment and satisfactions with HIV services, and engagement with peer navigation were explored through Wilcoxon rank-sum and Chi-squares tests. Significant associations were then explored by utilizing a random-effects multivariable logistic regression. This type of regression was used in order to account for potential intra-cluster correlations among FSWs who access HIV care from the same facility. Within our sample (n=211), there was a total of 11 different public and private clinics. Results from this random-effects multivariable logistic regression are expressed in terms of adjusted odds ratio (AOR) and 95% confidence intervals (CI). All analyses were conducted using the quantitative software Stata SE version 15.1.[18]

Qualitative data analysis built on the analysis conducted from Aim 1. While analyzing data from Aim 1 on the dynamics of quality of HIV care, the Student Investigator focused on capturing the experiences of FSWs with peer navigation and support as they coursed through HIV treatment and care services. Interviews were analyzed using a thematic analysis approach,[15] applying a combination of both inductive and deductive techniques. Freire's theory on critical consciousness[19,20] grounded the analytical process and provided a framework for what we expected to uncover in the analysis (for example, peer navigation/support and promoting agency). However, questions directly addressing the experiences with peer navigation and support were not included in the semi-structured, in-depth interview guides. As a result, many of

the findings for Aim 3 were based on emergent themes captured through the analytical exploration of the dynamics that contributed to the experience of quality of HIV care of FSWs. The findings for Aim 3 were based on conversations wherein FSWs spontaneously spoke about their experience with peer navigation and support when addressing questions related to (1) First time linking to HIV care; (2) Experiences with HIV treatment; (3) Positive and negative experiences in the HIV clinic environment; and (4) Recommendations for improving HIV care for FSWs. Throughout the coding and overall analytic processes, recurrent consultation with the research team allowed for a richer conceptualization and understanding of the findings surrounding peer navigation and support. Atlas.ti version 8.4.4[17] was used to managed the qualitative data.

### *Human Subjects Research*

The parent study received human subjects research approvals from the Institutional Review Boards (IRBs) of the Johns Hopkins University Bloomberg School of Public Health (Baltimore, MD), and the IDCP Unidad de Vacunas e Investigación and the Consejo Nacional de Bioética en Salud (CONABIOS) (Santo Domingo, DR). An amendment was submitted and approved to include the researcher as a Student Investigator in the project. These human subjects research approvals supported the investigation being conducted for all research aims.

#### Informed Consent

Prior to engaging in any study activity, each participant was informed of the study and provided oral consent to participate. Given high levels of discrimination and stigma experienced by the study population of FSWs, oral consent has been utilized to protect participants' confidentiality and avoid creating an additional risk for participants by asking them to provide signatures. Informed consent took place in Spanish by trained survey administrators. Prior to consenting participants for this study, survey administrators reviewed the informed consent process with the local research team in the DR (IDCP) handling the data collection activities. Each survey administrator provided a copy of the informed consent to participants and reviewed in detail with the participants the purpose of the study, the procedures of the study (including, survey administration, blood draw for HIV biomedical tests and medical chart review), potential risks and benefits to participating in the study, explained how data would be handled and confidentiality would be maintained throughout the study, and explained the voluntary nature of participating in the study. During the informed consent process, survey administrators addressed all questions raised by study participants.

Survey administrators were tasked to stop the informed consent process if they believe the participant was not competent to provide informed consent. Reasons for indicating a participant not competent to consent included: (1) Participant was below 18 years of age; (2) Participant was believed to be intoxicated with alcohol and/or recreational drugs; and (3) Participant had a psychological condition that made her unable to provide informed consent.

There were multiple components being addressed as part of the informed consent process. Women who met the eligibility criteria (See "Parent Study" section), were first asked to consent

to participate in the baseline questionnaire and blood draw. Next, women were asked to provide consent to be contacted for additional study interviews. Lastly, participants were asked to provide consent to be contacted for future research initiatives that may arise. It is important to note, that study participants are reminded in each study visit of the voluntary nature of their participation, and the research team always reviews the informed consent process prior to conducting any data collection.

Confidentiality

All members of the research team of the current study –including the Study Investigator, recruiters, survey administrators, and interviewers– have participated in extensive training on the importance of maintaining participants confidentiality. None of the data collected contains personal identifiable information and an identification code has been developed for each participant. In addition, participants that were part of the qualitative subsample were encouraged to avoid stating any personal names during the interview. If a participant did provide any personal information, this information was redacted from any transcriptions in an effort to maintain confidentiality. Moreover, all data collection activities were conducted in a private space at the IDCP offices.

Data Management

All survey interview data was captured electronically with tablets and uploaded using a secure server. All data was sent to the United States de-identified by the survey manager on a weekly

basis during the data collection period. Biomedical data was collected separately by the IDCP research team and sent separately for analysis de-identified, only using the participant code. Survey and biomedical data were merged by the research team in the United States using the participant code. All databases are password protected. In addition, audio-recordings, interview notes, and interview transcriptions collected as part of the qualitative subsample has been kept on a separate secure server during data analysis. Upon completion of the study analysis of the parent study, all audio-files will be destroyed. All paper forms (i.e., reports of AEs, consent forms, survey instruments) and tablets are store in locked cabinets in the IDCP offices.

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## Chapter 5: Respect and Resources: Exploring the dynamics of the HIV quality of care experienced by female sex workers living in the Dominican Republic (Manuscript 1)


### Abstract

**Background:** Despite increased attention and efforts to improve HIV treatment and care among female sex workers (FSWs), they continue to have suboptimal HIV outcomes. Exploring the socio-structural dynamics related to the quality of care received by FSWs is critical to further strengthen interventions to improve their HIV care continuum outcomes.

**Methods:** Utilizing a mixed methods approach, we employed qualitative in-depth interviews (n=20) supported by observational clinic assessments (n=11) to explore healthcare experiences and clinic's characteristics, resources and operations that contribute to the quality of care received by FSWs. Data was analyzed using a thematic analytic approach, while also employing descriptive statistics of the clinic data.

**Results:** Quality of HIV care experienced by FSWs was influenced by structural and relational aspects of care. Insufficient stock of antiretroviral therapy, financial burden created by HIV costs, lack of comprehensive care, and the physical clinic space were salient structural factors limiting FSWs' experience of quality HIV care. Quality of care was also closely linked to relational aspects of the HIV care environment, including FSWs' relationship and communication with their clinical providers. Lastly, agency, as witnessed through the action derived from FSWs' treatment literacy, emerged as an important factor contributing to the quality of HIV care- as FSWs' treatment literacy resulted in greater advocacy and demands for quality care.

**Conclusion:** Programmatic efforts should be directed to addressing gaps in the physical and social clinic environment, including addressing resource shortages, supporting comprehensive care, promoting positive and effective patient-provider relationships, and facilitating HIV treatment education opportunities for FSWs.

**Key words:** Agency, HIV, physician-patient relationships, cisgender female sex workers, treatment literacy, antiretroviral therapy, continuity of care, adherence, retention

## Introduction

Globally, female sex workers (FSWs) are among the most vulnerable populations in relation to their disproportionate burden of HIV.[1-11] The global HIV prevalence among this group is high at 10.4%, with the Latin America and Caribbean region having an estimated prevalence of 4.2% among FSWs.[6] Across all settings, FSWs have been found to experience significantly higher levels of HIV compared to all women of reproductive age between 15 to 49 years.[1,2,6,12-17] The evidence suggests that FSWs between 15 and 49 years have 13.5 times greater odds of being HIV-infected compared to women overall in low- and middle-income countries.[12,18] In the Dominican Republic (DR), FSWs have nearly 5 times greater odds to be living with HIV compared to other adults (HIV prevalence of 4.4%[9] vs. 0.9%[19]).

Despite increased efforts being made towards improving HIV treatment and care programming for FSWs, with estimates of engagement in HIV care and antiretroviral therapy (ART) increasing,[20] FSWs continue to have suboptimal HIV outcomes.[6,21,22] For example, a systematic review found that among FSWs living with HIV, 38% are currently on ART, and 57% of FSWs on ART are virally suppressed.[23] Among some of the socio-structural factors that contribute to FSWs' poor HIV outcomes include experiences of stigma and discrimination, violence, low literacy, and poverty and social instability.[7,20,24,25] In the healthcare environment, studies have found key factors that contribute to the poor attainment of HIV outcomes, such as linking to HIV care, ART initiation and ART discontinuation, at both the provider and clinic levels.[20,24]

At the provider level, research has highlighted the importance of the patient-provider relationship, with poor treatment from healthcare providers being linked with obstructing

successful linkage to HIV treatment and care.[20,24,26-28] In fact, FSWs' interaction with healthcare professionals has an effect on how they navigate through the healthcare system. For example, stigma related to sex work inhibits FSWs' ability to speak about their occupation candidly with healthcare professionals and as a result may stop them from obtaining the comprehensive healthcare they need including violence counseling and treatment for HIV and sexually transmitted infections (STI).[26-28] In addition, studies have shown that healthcare providers exhibit greater bias towards FSWs in general compared to those individuals living with HIV not engaging in sex work.[26] In fact, there is an independent (negative) association between sex work stigma and access to healthcare services.[3,26,29] A study by Nyblade and colleagues [30] found that healthcare workers engage in discrimination against sex workers at a high rate, with nearly 72% of FSWs in the study experiencing some form of sex work related stigma by healthcare providers.[30] This finding is alarming as it could effectively lead to the avoidance of formal health services among this group.[30,31] Furthermore, poor treatment by healthcare providers has also been associated with decrease ART initiation, increase ART interruption, and declines in ART adherence.[24,31,32]

The clinic environment also shapes the experiences of FSWs as it relates to their HIV care and could inhibit positive HIV outcomes among this population. Clinic level factors such as costs associated with HIV care, distance to healthcare facilities, rigid clinic policies, and healthcare facilities' inability to meet the demands for ART, have been found to obstruct HIV treatment and care.[20,24] Furthermore, as shown by Kennedy and colleagues, the inability of healthcare systems to have centralized services could also hinder FSWs' HIV care experiences as it creates further structural barriers for this community.[31]

Despite existing evidence on clinic and provider factors facilitating or obstructing the attainment of optimal HIV treatment and care outcomes among FSWs, research exploring the quality of HIV care among this population has been limited. More evidence is needed to explore how the clinical context and provider dynamics influence the quality of HIV care among FSWs as a strategy for strengthening interventions aiming to improve HIV outcomes among this population. The aim of this study is to explore the healthcare dynamics surrounding the quality of HIV care experienced by FSWs living in the DR by utilizing observational clinic data combined with qualitative individual in-depth interviews to provide a more holistic description of the HIV care environment and the experiences with HIV care of FSWs.

## Methods

### *Study Design and Parent Study Characteristics*

The current study is embedded within the NIMH-funded parent study titled "Stigma, cohesion and HIV outcomes among vulnerable women across epidemic settings" (R01MH110158). The parent study is a longitudinal observational cohort study being conducted in Iringa, Tanzania and Santo Domingo, DR. The parent study aims to assess the role of socio-structural and behavioral factors along the pathway to viral suppression among FSWs living with HIV and inform tailored and effective HIV prevention, treatment and care programs. In each of these two settings, a cohort of approximately 200 FSWs living with HIV has been enrolled and is being followed prospectively at 0, 12 and 24 months.

Eligibility criteria for participants in the parent study included being 18 years or older, with a confirmed HIV-positive diagnosis and having reported exchanging sex for money in the last month prior to enrollment. Women who did not meet the eligibility criteria or were unable to provide informed consent were excluded from the parent study. In the DR, participants were largely recruited through the aid of peer navigators from the sex worker-rights group MODEMU (*Movimiento de Mujeres Unidas*), key informants, and participants themselves.[8,9]

As part of the parent study, a subsample of 40 women (n=20 in Tanzania and n=20 in the DR) from the original cohort were invited to form part of a qualitative longitudinal cohort study aiming to explore the dynamic context of social cohesion and HIV and sex work related stigma among FSWs in relation to HIV services and outcomes. This qualitative cohort is being followed prospectively and will complete a total of three rounds of semi-structured, in-depth interviews (IDIs), with each interview being conducted annually since October 2018. This study utilizes qualitative data from the first two rounds of semi-structured, IDIs conducted with the qualitative subsample (n=20) from the DR.

The current study also draws from a clinic assessment conducted as part of the parent study. Informed by the quantitative survey data in each setting, information on participants' regularly visited HIV care facility was collected at the baseline of the parent study. This information was used to establish a list of HIV care facilities serving as the sample for the clinic assessment. The clinic assessment aims to assess the clinic environment and understand the dynamics and operations influencing the delivery of HIV treatment and care. This study utilizes the clinic level data collected from HIV clinical care facilities (n=11) in the DR.

*Qualitative Interviews*

*Data collection procedures*. Participants for the qualitative subsample were recruited using a stratified purposeful sampling approach,[33] sampling participants based on viral suppression at baseline. This approach resulted in the formation of a longitudinal cohort of 20 participants comprised of 10 virally suppressed (less than 400 copies/mL) and 10 not virally suppressed (400 or more copies/mL). All IDIs were conducted in Spanish by two trained interviewers in a private office at the IDCP (*Instituto Dermatológico y Cirugía de Piel Dr. Huberto Bogaert Díaz*) after securing informed consent from all participants. All 20 participants completed the first round of semi-structured, IDIs between October and November 2018, while 18 participants completed the second round of semi-structured, IDIs between December 2019 and January 2020. Each IDI lasted approximately 60 minutes.

*Data management and analysis.* All interviews were transcribed and analyzed in Spanish, and select quotes were translated to English for the purpose of manuscript development. Data analysis focused on the questions surrounding experiences with HIV care. In particular, we were interested in questions related to: (1) Participants' perceptions of their current HIV care; (2) Participants' understanding of their current HIV treatment; (3) Facilitators and barriers to receiving HIV treatment and care; and (4) Recommendations to improve their HIV treatment and care experiences. We relied on an iterative analytical approach using thematic analyses to allow for a deeper analytical exploration of the data within and across participants. First, each transcribed interview was read thoroughly prior to coding to allow for a deeper immersion into the contextual realities of each participant. Next, interviews were analyzed using a thematic

analysis approach[34] applying a combination of both inductive and deductive techniques. Analysis begun with a set of a priori topics or codes, while embarking on a deeper exploration by building on the data itself and allowing the emergence of new topics or codes. Throughout the coding and overall analytic processes, coding memos were used to describe changes to the methodology, begin to synthesize the data, and capture any relevant thoughts that could have implications in the conceptualization of results. Research debrief meetings with the study team were conducted to assess the dependability and confirmability of the results by engaging in rich discussions to explore all of the results in detail.[35] Atlas.ti version 8.4.4[36] was used to managed the qualitative data.

*Qualitative subsample characteristics.* **Table 5-1** presents the characteristics of the qualitative subsample. The median age of women included in this subsample was of 40 years (range: 21-53 years). Most women had an educational attainment of primary school (55%), while the remaining had secondary school or higher. Most women (70%) reported being single, separated or widowed, while 30% reported being in a domestic union. All women included in the sample were mothers. Regarding their HIV characteristics, the median number of years women had been living with HIV was 12 years (range: 3-38 years), while the median number of years women reported being on ART was 9.4 years (range: 1.6-21.7 years). The vast majority women (85%) were currently taking ART. While most women reported being adherent to their ART (88.2%), only half of the sample (50%) was virally suppressed.

**Table 5-1.** Characteristics of women participating in the qualitative cohort (n=20)

| | n | % |
|---|---|---|
| ***Individual Characteristics*** | | |
| Age (median, range) | 40 | (21, 53) |
| Education | | |
| Primary | 11 | 55.0 |
| Secondary | 7 | 35.0 |
| University or Post-Graduate | 2 | 10.0 |
| Marital Status | | |
| Single/never married | 5 | 25.0 |
| Domestic union | 6 | 30.0 |
| Separated | 7 | 35.0 |
| Widowed | 2 | 10.0 |
| Number of children | | |
| 1 child | 4 | 20.0 |
| 2 children | 9 | 45.0 |
| 3 children | 7 | 35.0 |
| ***HIV Characteristics*** | | |
| Years living with HIV (median, range) | 12 | (3, 38) |
| Currently on ART | | |
| No | 3 | 15.0 |
| Yes | 17 | 85.0 |
| Years on ART^ | 9.4 | (1.6, 21.7) |
| ART Adherence in the last 4 days | | |
| No | 2 | 11.8 |
| Yes | 15 | 88.2 |
| Viral suppression <400 | | |
| Not suppressed | 10 | 50.0 |
| Virally suppressed (<400) | 10 | 50.0 |

*Clinic Assessment*

*Clinic sample and data collection procedures.* A total of 11 HIV comprehensive care centers in the DR, 7 public and 4 private facilities, were part of the clinic assessment. Trained interviewers conducted the clinic assessments via direct observations of the clinic spaces and facilities, and through close-ended questions administered to clinic staff and HIV care providers. Data collection for the clinic assessment was completed between March and July 2019.

*Data analysis.* The assessment of the clinic level data was based on descriptive statistics of the quantitative data. We explored overall frequencies and proportions of the total sample (n=11), while also observing any commonalities or differences between the clinics by type of facility (public versus private). Interviewers' clinic qualitative observations were explored and used to refine quantitative findings and provide a fuller description of the clinic environment. All data was explored in Spanish utilizing Stata SE version 15.1.[37]

*Ethical Considerations*

This study received human subjects research approvals from the Institutional Review Boards (IRBs) of the Johns Hopkins University Bloomberg School of Public Health (Baltimore, MD), and from IDCP *Unidad de Vacunas e Investigación* and the *Consejo Nacional de Bioética en Salud* (CONABIOS) (Santo Domingo, DR). All participants in the qualitative study received 400 Dominican pesos (approximately $7 U.S. Dollars) in compensation for their time per interview.

**Results**

We organized the results of our paper into two domains: structural and relational aspects of quality of HIV care experienced by FSWs. Structural aspects found to be associated with the quality of treatment and care services included availability of resources, access to comprehensive care, the physical space, and cost of care. Relational aspects found to be influencing the quality of HIV care included the patient-provider relationship, continuity of care, and effective communication -explored through participants' readiness to understand treatment and implications of treatment.

*Structural Aspects of Quality of HIV Care*

*Institutional Characteristics of the Clinic Environment*

The vast majority of clinics operated 5 days a week, with only a single public facility providing services 6 days a week. Most clinics, both private and public, operated for at least 40 hours per week. Only a single private clinic and two public clinics operated for less than 40 hours per week. **Table 5-2** presents the institutional characteristics of the clinics by type of facility. Regarding the composition of the clinic personnel, most clinics had access to at least 1 doctor, with private facilities having a larger number of doctors compared to public clinics (median=5 versus 3, respectively). All of the private clinics had access to two nurses, whereas in the public facilities most had access to at least one nurse. Nevertheless, in one public facility it was noted that there was no access to nurses on site. Most clinics had access to at least 1 counselor, psychologist or social worker on site (median 3, range: 0-9), with private facilities having greater access to this type of staff compared to public facilities (median= 4.5 versus 3, respectively). In fact, in one public facility there was no access to this type of support staff. Public facilities relied more heavily on HIV peer support compared to private facilities (median=2 versus 1, respectively). In fact, all public facilities reported having at least 1 HIV peer support working on site, while one private facility had no access to this type of support staff. No public clinic had access to nutritionists on site, whereas two private facilities were supported by 1 nutritionist on site for each (data not shown in table). Overall, private facilities had a slightly larger volume of active patients living with HIV compared to public facilities (median 1172 versus 848, respectively). In addition, almost all (89.9% in public and 98.5% in private facilities) active patients in both private and public clinics were currently receiving ART.

**Table 5-2.** Institutional characteristics of clinics by type of facility

| | Total (n=11) | Public (n=7) | Private (n=4) |
|---|---|---|---|
| ***Composition of Clinic Personnel*** | | | |
| Number of Doctors | 3 (1, 21) | 3 (1, 6) | 5 (1, 21) |
| Number of Nurses | 2 (0, 2) | 1 (0, 2) | 2 (2, 2) |
| Number of Psychologists, Counselors, or Social Workers | 3 (0, 9) | 3 (0, 9) | 4.5 (1, 9) |
| HIV Peer Support | 2 (0, 4) | 2 (1, 4) | 1 (0, 4) |
| ***Patient volume*** | | | |
| Number of active HIV patients (median, range) | 952 (279, 4,523) | 848 (279, 3,212) | 1171.5 (863, 4,523) |
| Number of HIV patients at this facility are currently on ARV drugs (median, range) | 851 (279, 4,523) | 762 (279, 3,093) | 1153.5 (764, 4523) |
| Proportion (%) of active patients on ART | 89.4 | 89.9 | 98.5 |
| ***Experiences with HIV Care*** | | | |
| Typical wait time patients spend in waiting room prior to receiving care | | | |
| 30-60 minutes | 9 (81.8) | 6 (85.7) | 3 (75.0) |
| 1-3 hours | 1 (9.1) | 1 (14.3) | |
| 4 or more hours | 1 (9.1) | | 1 (25.0) |
| Typical length of time for an initial HIV visit | | | |
| 15-29 minutes | 1 (9.1) | 1 (14.3) | |
| 45-59 minutes | 2 (18.2) | 2 (28.6) | |
| 60 minutes or more | 8 (72.7) | 4 (57.1) | 4 (100.0) |
| Typical length of time for a follow-up HIV visit | | | |
| Less than 15 minutes | 1 (9.1) | | 1 (25.0) |
| 15-29 minutes | 7 (63.6) | 5 (71.4) | 2 (50.0) |
| 30-44 minutes | 2 (18.2) | 1 (14.3) | 1 (25.0) |
| 45-59 minutes | 1 (9.1) | 1 (14.3) | |
| Typical wait time at the dispensing room before receiving ART stock | | | |
| Less than 15 minutes | 6 (54.5) | 4 (57.1) | 2 (50.0) |
| 15-29 minutes | 3 (27.3) | 2 (28.6) | 1 (25.0) |
| 45-59 minutes | 1 (9.1) | 1 (14.3) | |
| 60 minutes or more | 1 (9.1) | | 1 (25.0) |

**Table 5-2** also provides information on the observed experiences of patients in the clinic environment. Based on the clinic assessment, in most facilities (81.8%) patients spent between 30 to 60 minutes waiting to receive care, though in one public clinic patients waited between 1 to 3 hours in the waiting room prior to being seen by a medical staff, while in another private clinic the wait time was 4 hours or more. The typical length in time for the first initial HIV visit for most clinics was 60 minutes or more (72.4%), while the follow-up visit for most clinics was typically between 15 to 29 minutes (63.6%). In most clinics the wait time to disburse ART to patients was less than 15 minutes (54.5%), though in one private clinic this wait time could be 60 minutes or more.

*Availability of ART in the Clinic Environment*

**Figure 5-1** presents the available ART resources by type of facility. When exploring the number of months in the past year wherein facilities have had insufficient ART stock, only 3 public clinics and 2 private clinics reported not experiencing any shortage of ART stock. In public facilities, one public clinic experienced a shortage of ART stock for 1 month, two public clinics for 2 months, and an additional public clinic experienced an ART shortage for a total of 7 months. In contrast, in private facilities, one private clinic experienced an ART shortage for 3 months, while in another private clinic the shortage of ART had been for 4 months.

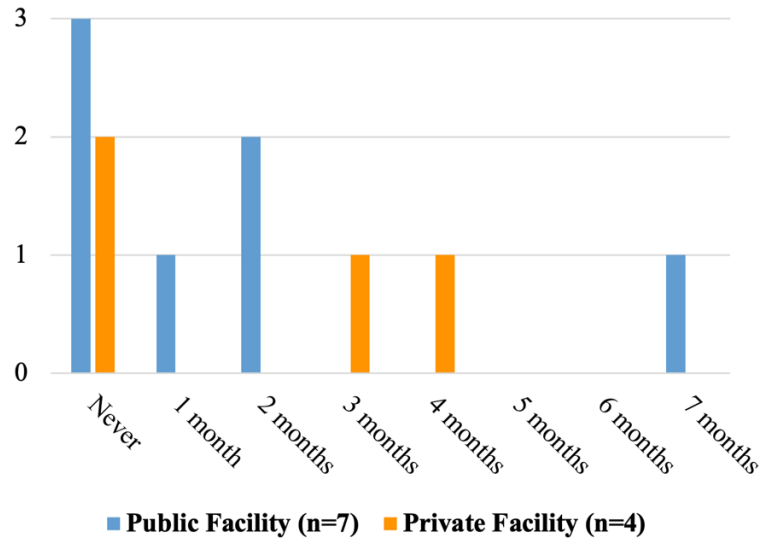


**Figure 5-1.** ART shortage by type of facility

Women were impacted by the observed ART shortage experienced at the clinic level. In fact, for some women it was impossible to describe their experience with HIV care without addressing their frustration and anger with their clinics' inability to provide ART to patients in a timely manner, often affecting their own ART adherence. In one instance, a participant described her experience going back and forth to the clinic to collect her ART, only to be turned around due to insufficient ART stock:

> *"I worry, and right away I go back [to the clinic] and [the healthcare providers] tell me, come back tomorrow, come back the day after, that there are no [ART] medications and I tell him 'you are going to let me die because I cannot last three days, four days without those medication since I stop taking those [ART] medicines I feel like my body is like a, like a current that passes me, no,'... and I told him let's see what [providers] are going to do, let's see, because I can't stand it [her side effects of not having her ART medication]..."* [32 years old, 7 years living with HIV]

For some of the women who were affected by their clinics' ART stock shortage, the shortage also led to a change in their ART regimen. In this next example, a woman explained her exasperation towards her doctor and her clinic because of their reluctance to provide her with her preferred ART regimen, which had worked well for her, due to insufficient ART stock. She recalled her provider trying to place her back on a previous ART regimen that had caused many side effects:

> *"I told [my doctor], I am not going to take the medicine, I am not going to take the Stocrin, I am not going to take that. Here [at the clinic] there are too many medicines that you can change me to, but ah there is no [ART medicines], there was none and the shortage began. There are no [ART] medications so they gave me one and [then] a month later, it was scarce…I took a single month of that [ART medication] and already [you are telling] me [that there is not enough]."* [53 years old, 38 years living with HIV]

Despite not all women being affected by the ART stock shortage, and continuing with their current and preferred ART regimen, there was still a fear that the ART shortage could impact their treatment. One woman commented the following:

> *"[I am still with] the same [clinic], with the same [ART] treatment. Though recently I was afraid… because there was a shortage of medicine [at the clinic], I don't know if you remember, there was a month that there was a shortage of medicine and there were people who were changed [to a different ART regimen]. There were people who took a medicine, then when they went to the [clinic], there was no medicine and they were put on another one, and when the next appointment came, there was no [more medicine] and then they were put [on yet] another and I was stressed with that because I didn't want to change my [ART medication]…Because my medicine works for me."* [41 years old, 3 years living with HIV]

Not surprisingly, a recommendation to improve the quality of HIV care centered on the clinics' ability to secure the adequate amount of ART stock to properly deliver medication to their patients. This would in turn help reduce the number of ART regimen changes that some women have experienced, which some attributed to insufficient ART stock. One woman expressed the following:

> *"Take good care of patients that live with [HIV]…because the lack of medicine is a problem, and my medications change a lot. I do not like that."* [32 years old, 7 years living with HIV]

When exploring the distribution of ART supply to patients (**Figure 5-2**), most clinics (4 public and 3 private) provide patients with a 2-month supply of ART, with an additional 2 clinics (one public and one private) providing patients with a 3-month supply of ART. However, this clinic assessment varied somewhat from women's reported experience. According to the qualitative interviews, some women would have to go to their clinics once every two months, once a month, and even once every 15 days depending on the current ART stock. More importantly, even if the clinics could guarantee sufficient ART stock, for some women who were not doing well with their treatment (as determined by increased viral load and decreased CD4 count), they would often be placed on a schedule that required them to come into the clinics to collect their ART once a month.

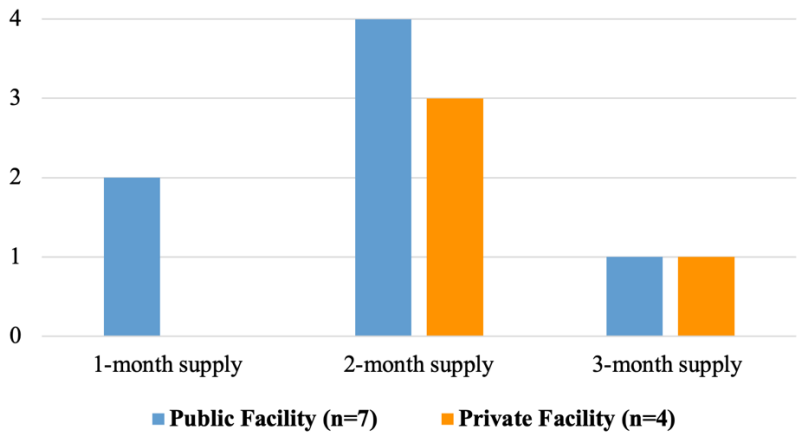


**Figure 5-2.** ART supply distribution by type of Facility

*The Financial Burden of HIV Care*

Some women described the financial hardships that they experienced as a result of accessing HIV care. High clinic visitation frequency, mainly due to ART distribution (see section above on "Availability of ART in the Clinic Environment"*)*, placed a significant financial strain on many women, as going to the clinics often implied being there for many hours, and financially some cannot even purchase food to eat while they wait to be seen by a doctor or to retrieve their medication. One participant recalled:

> *"Today you get there [to the clinic] at seven in the morning and it is still two and three [in the afternoon] and you are there, there is a lot of people [waiting], sometimes I tell the person at the pharmacy, look, they will have to give me half of their food because I am hungry."* [49 years old, 7 years living with HIV]

Other women also explained that transportation alone, getting to and from their clinics, created a heavy financial burden. In the following quote, one woman explained the financial strain that is placed by transportation, she continued by breaking down the total cost due to transportation:

> *"… from [the neighborhood where I live] I pay 45 [Dominican Pesos] to get on the bus, but sometimes the bus takes a long time and you have to leave early because at 12pm they close [the clinic] and you have to take a motor for 50 Pesos…and then another 25 [Pesos] for a bus or 25 [Pesos] for a car, and that is already 75 [Pesos] and if you are going to pay 25 Pesos more to the clinic [for fees] well that is already 200 [Pesos], now you don't even have for breakfast."* [53 years old, 20 years living with HIV]

The same participant also explained that given the financial burden of transportation alone, she is sometimes able to arrange for her provider to deliver her medication to her home or to arrange a meeting point (outside of the clinic) where she can meet with her provider and collect her ART refill. She further explained:

> *"Yes, I call my [provider], '[hey, look, I don't have [ART] medicine' and sometimes she says 'I'm going to take it to you' or if not, 'we are going to meet at [a local park closer to my home] because she [lives closer to me] and sometimes you don't have the money to go to the clinic because it is 200 [Dominican Pesos] for the trip, and sometimes you don't have it."* [53 years old, 20 years living with HIV]

For some women not having enough money to pay for transportation led to missed HIV care appointments. As explained by one 41-year-old woman who has been living with HIV for 12 years: *"in the past I had difficulties, I would miss my appointments because I couldn't pay the fare."*

Some women recalled a type of program by the clinics that allowed them to obtain some money for their groceries that would serve to alleviate the financial hardship they are experiencing,

which is exacerbated by their HIV care. Women who had access to this type of financial opportunity spoke about this program with nostalgia and with a desire to have the program operate regularly, as this is a type of help that appears to be unpredictable - they could only count on it some of the time. Two participants recalled this service:

> *"I find that here [in this clinic] they help me more, they really do. Here they help me more because here twice I got my money for groceries, but then they said that they took it away, I don't know why, but that money for groceries helped me a lot at home."* [25 years old, 3 years living with HIV]

> *"Sometimes you see that people give the [clinic staff] help to give to us. Before [the clinic] gave you [food] or a little money for groceries and now not even that."* [37 years old, 12 years living with HIV]

Lastly, despite the DR offering ART free of charge for people living with HIV, one participant also expressed the fear that she has of the medication being offered at a cost. This 21-year-old woman, who was diagnosed at birth with HIV, explained that she has a child to take care of, and he comes first and *"no one should be paying for [ART] medication."* This participant has also had difficulties picking up her ART given the financial struggles that she is experiencing, which are only aggravated by a clinic fee she would be responsible for when she goes to her appointments.

*Availability of More Comprehensive Care*

Regarding additional services offered by clinics (**Figure 5-3**), most clinics, both public and private, offered STI testing and care services on site (5 public and 3 private), though this service

(STI testing and care) was not offered in one public and one private facility. Furthermore, in one public facility STI testing was offered to patients, but there were no services for STI care available on site. In addition, though all private clinics reported offering treatment for tuberculosis on site, this service was only offered in five out of the seven public clinics. Lastly, all but one public facility had the ability to distribute condoms on site, while all private clinics provide condoms to patients.

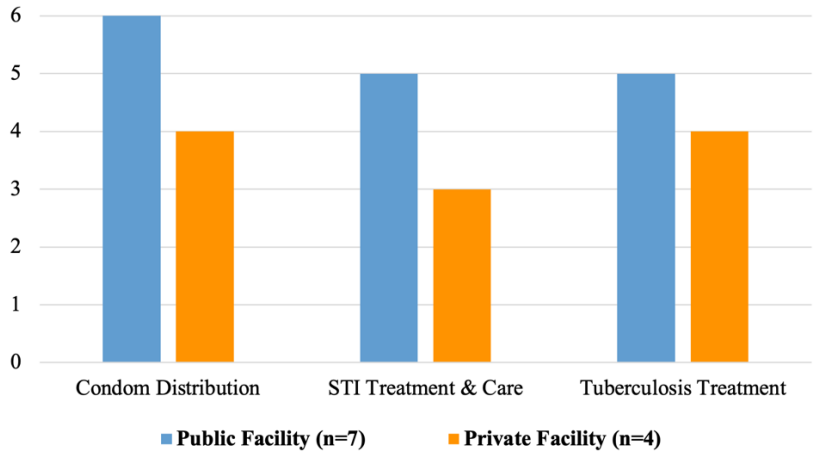


**Figure 5-3.** Other services by type of facility

Delivery of more comprehensive care services on site was reported as a factor that could improve the experience in HIV care for FSWs. In particular, one woman recommended that, as a sex worker herself, there is a need to have more comprehensive care, such that one could receive STI and HIV care in the same location. This participant explained:

> *"I would like to have a program where any other STI is treated for women because we are sex workers and most [sex workers] are exposed…when a sex worker goes to get treated for an STI at a health center she suffers discrimination, then a space like this, that they can go to a person who knows that all the women who come here are sex workers,*

> *you are not going to be surprised because you know that everyone who comes here is not going to put on the medical gloves [to discriminate you], they put on a medical gloves because they have a health protocol but not because of discrimination."* [41 years old, 3 years living with HIV]

*The Physical Space*

The clinic observation assessment also revealed that though most waiting rooms in both public and private facilities were "comfortable," in one public facility interviewers noted that the waiting room was in "poor condition." In addition, in another public facility the waiting room was described as having an insufficient number of chairs and poor coverage from the rain, as one interviewer noted that "if it rains you get wet." Most clinical consultation offices within these public and private facilities were described as being "comfortable," though in one public facility consultation rooms were described as being in "poor condition." In clinics, both private and public, with support staff like psychologists, counselors and social workers on site, interviewers also noted that they had "adequate" and "comfortable" spaces to treat patients. Overall observations of the clinic space revealed some differences between public and private clinics, public facilities were often described as being "too small" for the high influx of patients treated in these sites. One interviewer captured this sentiment stating:

> *"They treat way too many patients and the infrastructure is very small."* (Public Facility)

In another instance, an interviewer indicated that the small space in the public facility also led to the sharing of offices for different healthcare related tasks:

> *"They use the same space for counseling, archiving medical records, and handing out medications."* (Public Facility)

Most general comments about private facilities indicated that these sites were "comfortable." In particular, one clinic was described as having a "pleasant and friendly atmosphere" while in another clinic the interviewer described the facility as being "well-organized." In one private clinic, though there were no mentions of inadequate conditions of the clinic, the interviewer did note that some spaces on the site were "too small."

The physical space was also an important attribute when thinking about the experiences of HIV care for women. In fact, one participant reported the limitation and risk that inadequate spaces imposed on her HIV care experience. This participant suggested the there is a need to address the clinic infrastructure to ensure more private spaces for one to utilize while waiting to be seen or waiting for medication due to fear of disclosing her HIV status to others inadvertently. She explained:

> *"Personally, I would like to [get the medicine] sent to me, but the first thing would be that they don't have me sitting there in public, where so many people arrive that even I have come across people who know me several times…That is my biggest fear, because it is not something that you arrive and you are going to wait a minute, ten minutes, it is something that you are going to last sometimes up to two hours sitting down…That waiting time is frustrating for me, it's frustrating for me because it's a public setting there."* [28 years old, 6 years living with HIV]

*Relational Aspects of Quality of HIV Care*

*The Patient-Provider Relationship*

Women would often recall their own patient-provider relationships and their last interaction with their providers to offer insight into how they were doing and feeling about their HIV care. For many participants, being treated with respect and dignity by their healthcare providers was an indication of experiencing good HIV care. A 53-year-old participant who has been living with HIV for 38 years explained how she feels good about her current HIV care because her doctor treats her well, her doctor treats her *"like family."* In explaining how her current care was going, another participant expressed the following:

> *"[Providers] treat me well [at the clinic] all the time, I don't think there are people who do not go there because those people treat you well, it can be your final stage, [and they treat you] with a lot of love, with a lot of affection."* [53 years old, 20 years living with HIV]

For some women the discussion around their relationship with their providers and the type of treatment they received also involved the type of information that they are receiving from their providers. Women would expand on how this information was framed and delivered by their doctors (particularly in terms of the information needed to remain healthy). One participant explained:

> *"[I feel] good [with my HIV care], because they explain to you how you have to take care of yourself…they tell you that the main thing is [taking] your medications each day, that you should not miss your appointment, because sometimes you go to the appointment to look for the medications but you may have another problem that does not have to do with your medications, and [they also tell you] what needs to be tested, viral load, hepatitis B…"* [39 years old, 14 years living with HIV]

Furthermore, for some women having access to their providers outside of the clinic to answer questions or concerns that they may have was also an attribute of a positive patient-provider dynamic. As one woman recalled:

> *"[My providers] make things easier for me, as I am so far away,…I just have to write on WhatsApp…I write to them on WhatsApp, 'look, I'm like this, I got an allergy.' [proceeds to explain the allergic reaction she experienced] I sent him a photo on WhatsApp and he told me to drink anti-allergy drugs and I didn't have to come [to the clinic]; And I feel good because despite everything they try to help you as much as they can."* [37 years old, 12 years living with HIV]

Women also focused on the type of emotional support that their providers gave them as part of this positive patient-provider relationship. Women would recall how their providers have asked them "how they are feeling?", "how everything is going for them?" and these are important questions that showed them the type of caring practitioners they are and the type of support they could receive from them. One woman recalled the conversation she had with her provider when she was not managing her HIV diagnosis and treatment well:

> *"[My doctor] spoke very well to me, she advised me about my life how I have to live life, 'don't let people get to you,' when I hear people talking about anything [about me]. She always thinks that I am very important, [more] than anything that 'I have to love myself.' Few [doctors] have told me that…she is very kind, and then there are [other doctors] that are like little girls with little knowledge, I find myself [thinking], they are about 17, 18 [years old]. I see them like that."* [41 years old, 12 years living with HIV]

Despite not many women discussing whether or not their providers knew about their sex work occupation. One 37-year-old woman who has been living with HIV for 7 years explained how that information would not be relevant to disclosed as *"those are her own personal things."* This woman also indicated not discussing with her provider how alcohol consumption could affect her treatment, despite this issue coming up in her interview. On the contrary, one woman did suggest that her provider knows about her sex work occupation, and in disclosing that type of information, she has had the opportunity to better advocate about what doesn't work for her regarding treatment. She explained:

> *"There was something that the doctor told me,…he told me because my viral load was twenty, because it was undetected and now it is whatever [alluding to a high viral load], he told me 'you are not taking the medications correctly.' I say, 'no doctor, it is not that I am not taking it correctly, what is happening is something, that is, I am working in the street sometimes if the medicine [I have to take it] at 9 in the morning and at that moment I'm not in the right place to take it or I take it an hour later or two hours later or when I remember or something like that' he said 'no, you set an alarm or see how to organize yourself.'"* [39 years old, 19 years living with HIV]

While most women focused on the positive aspects of the relationship they have with their providers, some woman also described instances when their providers did not treat them well and when they found their providers to be disrespectful. In one instance, one woman described the negative relationship she had with one provider, which led to her transferring to another clinic for her HIV care. While explaining why she needed to transfer to another clinic, this participant recalled that her provider was not being forthcoming in explaining to her the rationale for why

her ART treatment was being changed so often. She also recalled her provider's behavior towards her as an additional component guiding her decision to transfer to another clinic:

> *"And a doctor who is kind of rude…he was very rude to everyone, and spoke badly, he spoke badly to me and I am one of the people who do not like to be spoken to badly, that is, I do not like to be disrespected so I do not disrespect anyone because as the saying goes you need to be respectful to others so others can respect you. If you do not respect me, then don't expect me to respect you."* [21 years old, diagnosed with HIV at birth]

When women thought about how their experience in HIV care could improve, it was not unexpected that some women focused on improving the patient-provider relationship. Women stated that they should be treated "well" and care should be provided with respect and dignity. As one woman suggested:

> *"[My recommendation is for doctors to] be more educated, that is why there is education, that is why they went to school to [learn] that a patient is spoken to with dignity…Not like animals, it's like, for example, I'm a cashier, don't tell me that while I'm a cashier, I'm going to speak badly to the customer, because then I'm the one who loses."* [21 years old, diagnosed with HIV at birth]

*Continuity of Care*

Among women who reported receiving care by different providers, there was a sense of frustration in not having the same provider delivering HIV care during each visit. Seeing a different provider inhibited the ability of women to build trusting relationships with them. One woman explained her frustration at the current changes experienced at her clinic, where she once used to see the same provider, but has now started seeing a different one during each visit:

> *"Now they send me another doctor, every time there are different doctors…Every time a different face. No, [I don't like that]. There was a good one,…, that was here stable, [that] looks good. [Now] every time you come, there is a different face, sometimes they treat you well, sometimes they treat you badly."* [32 years old, 7 years living with HIV]

Despite not all participants rejecting the idea of seeing a different provider during each visit, there was still a clear preference for provider continuity. As one participant discussed how she is treated by a different provider each time, she was also discussing with the interviewer her strategy for obtaining care by the same provider next time she has an appointment:

> *"Doctors, there is no fixed doctors there. There are some people who have one, but I didn't know if one could meet with [the same] one [each time], because with the [doctor's] name you could say 'I want to see myself with so-and-so', but I didn't know. Yesterday I saw a different doctor, but all the doctors treat me well, they are very affectionate, they speak very well to you. But yes [next time I go to my appointment I want to see the same doctor]. The one who treated me yesterday. I didn't see her name, no, I'm going to find out her name."* [41 years old, 12 years living with HIV]

For some participants, lack of continuity of care presented a barrier to obtaining appropriate HIV care. In particular, participants would often deal with clinic confusion about basic information, such as ART regimen the patient is on, that would lead to distrust in the health care system. One participant explained:

> *"Because there are doctors, look on one of these days they could not even find my chart, one [doctor] did not even see my chart, how are they going to give me the [ART] medicine if they did not find my chart, unless they know by heart what I was taking…,*

*and I said 'but come on here, a [medical] chart cannot disappear the day that you know [the patient] has an appointment', [they say] there was a change [of staff]."* [39 years old, 14 years living with HIV]

Another woman explained the importance of continuity of care in enhancing the ability of patients to form more trusting relationships with their healthcare providers. This participant expressed that promoting continuity of care would help improve the overall HIV care experience. She explained:

*"Yes, I would like to have only one doctor…Sure, because as I said, there are things that you only share when you only have one doctor like when I was with [my previous doctor], there is trust and that whatever happened to you, you could say it, but when you see one today, one tomorrow, one the other day, another one on another day, and another one you just don't have that same trust."* [41 years old, 12 years living with HIV]

Interestingly, lack of continuity of care also led to some participants' asserting more control over their health and treatment. The same distrust in the health care environment that stemmed from lack of continuity of care, was often met with participants' increase agency about how to navigate the health care environment. As one woman described:

*"They give me a ticket [to be seen by doctor]. There I wait for my turn with the ticket, then they call me, we get stuck in a little room, sometimes [the doctor] forgets [my ART regimen] if I don't walk with the medicine container [in hand], there are no medicines for me every time I go, I always carry my container in my purse because well there are doctors, there are different doctors, so [I do this] so they don't give me [the wrong treatment] and kill me…because sometimes the doctor says if I don't walk with the container, he won't know what medicine I take. Because they don't search the chart*

*much. Or if you tell them the name of the drug, they will find it for you. Many times I have been left without medication because I forgot the container."* [32 years old, 7 years living with HIV]

*Effective Communication: Exploring Participants' Treatment Literacy*

Most women were able to refer to their viral load results as an indicator for assessing their health and current HIV status. Furthermore, women often attributed ART adherence as the main factor that contributed to achieving a "good" viral load. As explained by two participants:

*"Being virally suppressed means that the virus is suppressed just like the word says, that is, that the medicine keeps the virus locked in, so to speak, boxed, it is suppressed and the medicine does not allow it to leave [from] there to destroy my CD4, and destroy my body*." [41 years old, 3 years living with HIV]

*"CD4 are our defense, we explain like this, look, you see the CD4s, those are your good policemen, if those good policemen you are eliminating them, you get into trouble, you hear, and the viral load those are the bad ones, while your viral load is higher, your virus is higher, now if you take your medications just like you are supposed to, and you go to your appointments, because that also is part of it, because adherence is not only taking the medication."* [39 years old, 19 years living with HIV]

When probed about whether women knew if they had an undetectable or detectable viral load, or when expanding on their most recent viral load and CD4 test results some women had difficulty being able to fully express their understanding and address treatment literacy questions. These participants noted that they rely on their providers to let them know if something was not okay during their appointments.

*"I always sometimes find it difficult to understand the usual, they have explained it to me, but I always find it difficult to understand viral load with CD4. [Interviewer explains viral load and CD4]. Yes, it is always difficult for me and when I ask the doctor, what is it that has to be high? And [the doctor] stares at me, but tell me if it is that I don't remember."* [30 years old, 13 years living with HIV]

*"No [I don't know what viral suppression or what undetectable is], and look that I'm with [my doctor] today. She gave [my analysis results] to me today that I had done, but since I can't read it…They give them to me, I give it to the doctor and when the doctor sees them she says to me 'Ah! No, it is all good'"* [37 years old, 12 years living with HIV]

For some women, having an understanding of their treatment and how viral load and CD4 count were affected by treatment allowed them to better advocate about their health and address provider concerns regarding their own level of adherence to medication. While discussing her current viral load status, one woman explained her concerns given her own level of adherence:

*"[Doctors] tell me I am not taking [my medication]… I take the medication, then I tell [my doctor] yes, yes, that he has to know that [the medications] are not doing anything to me because I am sure that I am taking it. No, no [he has not sent me to get tests done]. [Apart from viral load] he hasn't told me to do anything, so that's what I want him to do for me [to get more tests done]. Because one time that happened when I didn't take [my medication] as I told you, it happened that I wasn't doing anything and they changed it to another [medication because the viral load went up]… [But this time], it didn't come out [the viral load results were high] and like I was doing so well, it didn't come out as I was [doing well]."* [43 years old, 18 years living with HIV]

## Discussion

This study combines clinic level data with insights from individual qualitative interviews among FSWs to provide a holistic description of the dynamics that shape the HIV care experience, including the structure and quality of care in this population. Our study highlights two important components that together work to impact HIV care and subsequently could impact HIV outcomes. Specifically, our results acknowledge the impact that structural and relational aspects of care have in influencing the quality of HIV care experienced by FSWs. Furthermore, our results recognize the contribution that a person's agency has on the HIV care experience.

As past studies have demonstrated, dissatisfaction with the clinic environment could lead to disengagement in HIV care and poor HIV outcomes;[24,31,38-40] as such, the clinic environment and procedures, or structural aspects of quality of HIV care, are a component where attention is warranted in order to ensure the appropriate delivery of care. First, as detailed in our results, it is important to consider clinics' ability to keep a sufficient stock of ART when working with all people living with HIV (PLHIV), including vulnerable groups like FSWs. The shortage of ART stock created a significant obstruction in the HIV treatment and care experience of FSWs given that it resulted in multiple clinic visits to receive ART medication (since the supply was being delivered for a shorter duration), or as women were being asked to come back to the clinic at a later time to collect ART refills. Most importantly, insufficient ART stock also led to changes, sometimes multiple, in the ART regimen for patients who had otherwise been satisfied with their treatment due to its effectiveness and their familiarity with it. Furthermore, our findings underscore how imperative it is for the clinics to address the ART stock shortage as this

medication shortage impacted FSWs' ability to control their own treatment adherence. This supports evidence linking ART shortages with poor treatment adherence.[24] In addition, our study found that the costs associated with engaging in HIV care services creates a significant barrier for FSWs' ability to sustain engagement with care services and often resulted in the disillusionment of engagement in formal HIV care. Transportation costs, in particular, were often mentioned as a main deterrent to being able to access HIV care and being satisfied with the current HIV care services. In particular, participants expressed that high frequency clinic visitation demands, often linked to medication pick-up, generated a financial strain for them and their families as it implied having to deal not only with transportation costs, but possible clinic fees and food consumption costs as well. These associated HIV care costs inhibited FSWs from full satisfaction of HIV care services, with FSWs indicating the need to provide assistance in the form of monetary contributions or vouchers for groceries to alleviate the financial strain. Similar studies among more generalized populations of PLHIV have also highlighted the need to address structural barriers, specifically transportation challenges, as evidence suggests these barriers obstruct PLHIV's ability to engage and be retained in HIV treatment and care services.[41,42] Furthermore, there is a need to recognize the unique needs of FSWs living with HIV. Our clinic assessment revealed that not all clinics provide more comprehensive care to include, for example, STI treatment and care. As illustrated in our results, having more centralized and comprehensive services for FSWs, extending beyond HIV care, could facilitate better care for them, while protecting FSWs from being subjected to stigma and discrimination in healthcare settings.

Another key component to the delivery of quality HIV care services relates to the relational aspects of care. FSWs often focused on the interpersonal aspects of care and the personal connections they have established with their providers as testaments to the delivery of quality HIV care. The patient-provider relationship proved to play a significant role in how FSWs navigated their own treatment and care. Experiencing poor treatment by providers -such as being treated carelessly, without respect or dignity- was noted as being a barrier to accessing quality HIV care and would often lead to the disruption of FSWs' current HIV care services, as women would often seek to terminate their current care and request a referral to other clinic locations. Women also reported an appreciation for healthcare providers that share clear and complete information as it relates to their HIV care and treatment. Unsurprisingly, FSWs recommendation to improve the quality of HIV treatment and care services also included a call for respectful treatment by healthcare providers. Studies have found that discrimination or being treated with contempt or disrespect by clinical care providers could hinder engagement and retention in care,[43,44] as such delivering care with dignity forms a central aspect of how we assess the quality of care being rendered to patients. Sensitivity trainings of all clinical care providers could aid in promoting more compassionate clinic environments and foster positive and more trusting patient-provider relationships. Furthermore, in line with FSWs focus on the relational aspects of care, there was a call by participants to promote continuity of care in the HIV clinic environment. Our findings suggest that FSWs desire to build more trusting relationships with their healthcare providers, and being exposed to different providers during clinic appointments thwarts their ability to form connections and engage in more open dialogue.

The last component that was highlighted by our study is FSWs' agency or their own capacity to have control over their own HIV treatment and care experiences. Results from our study indicated that FSWs were able to exert their own agency- via their own immersion in understanding their treatment and the biological implications of their treatment- to better advocate and demand for quality HIV care services. As FSWs gained a deeper understanding of their treatment and the effect of treatment on their own health, they were able to understand the impact of treatment adherence on their ability to achieve viral suppression or an undetectable viral load. With this information, FSWs were able to better discuss treatment expectations, barriers to adherence, or the need to change to other treatments. In our study, it was understanding the effects of treatment adherence on viral load which led to patient-led discussion on possibility of treatment resistance. For example, a participant's understanding of the correlations of low viral load with increased ART adherence, led to demanding further testing to be done by providers in order to uncover why viral suppression was not being reached despite treatment adherence. Furthermore, despite women having a strong penchant for continuity of care, our results also highlight how FSWs exert their own power and agency over their treatment when placed under a care environment wherein they are unable to trust their healthcare providers due to inability to rely on the consistent delivery of care by the same provider during each appointment. As such, though FSWs view provider discontinuity as an impediment to obtaining good quality care, it inadvertently promoted greater agency among women finding themselves in this situation. Though findings on health literacy and HIV have been inconsistent,[45,46] our study provides more evidence on the potential barriers that health literacy surrounding HIV treatment and care may have on how PLHIV access care and select appropriate treatments.

This study is not without limitations. FSWs who are part of the parent study were recruited through the *Abriendo Puertas* intervention,[8,9] peer navigators, other key informants, and through women themselves, and as such women in our study would have discussed their HIV status to at least one other person, and through the knowledge of the *Abriendo Puertas* intervention are likely to have already established their own engagement with HIV care. Nevertheless, our study aimed to fully capture the experiences surrounding their engagement with HIV care, which expanded to understanding factors that have led to this engagement. As such, we believe the findings of our study present an important contribution to understanding the dynamics that contribute to the experiences in care of FSWs living with HIV.

Findings from this study have important implications for how programmatic efforts address and assess the quality of HIV care among FSWs. These findings provide an opportunity to understand the most pressing aspects that shape the quality of the HIV care experienced by FSWs, and thus affect FSWs' pathway through the HIV care continuum. Our study highlights the importance of addressing the vulnerabilities of the physical and social clinic environment by ensuring the availability of resources, fostering more comprehensive care services, promoting positive and effective patient-provider dynamics, and facilitating opportunities for education and comprehension about treatment- as fostering treatment literacy created a pathway for promoting agency among FSWs leading to their self-advocacy and ability to make demands for better treatment and care services.

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## Chapter 6: Assessing the relationship of HIV quality of care on ART adherence and viral suppression among female sex workers living in the Dominican Republic (Manuscript 2)


### Abstract

**Background:** Female sex workers (FSWs) living with HIV continue to experience sub-optimal HIV outcomes. Focus on antiretroviral therapy (ART) based prevention efforts as means to address the ongoing HIV transmission underscores the need to understand the associations between quality of HIV care, treatment literacy and FSWs' pathway to viral suppression. This study aimed to assess the relationship between the quality of care and treatment literacy on ART adherence and viral suppression among this population to inform future programmatic efforts.

**Methods:** Using survey and biologic data from an existing cohort of FSWs living with HIV (n=211) in Santo Domingo, Dominican Republic, we conducted random-effects multivariable logistic regressions assessing the relationship between quality of care, measured through process and structure of care factors, along with treatment literacy, on ART adherence and viral suppression.

**Results:** Among participants, 79% reported ART adherence in the last 4 days and 76% were virally suppressed. Relational factors of the HIV care experience were significantly associated with viral suppression, with odds of viral suppression increasing with better patient-provider communication (AOR: 1.04; 95% CI: 1.01-1.07) and respectful treatment in the HIV clinic environment (AOR: 2.17; 95% CI: 1.09-4.32). Paying above the median cost for HIV care reduced both the odds of reporting ART adherence (AOR: 0.57, 95% CI: 0.34- 0.95) and being virally suppressed (AOR: 0.59, 95% CI: 0.41-0.85). Lastly, greater treatment literacy was

associated with an increased odds of reporting ART adherence (AOR: 4.15 for understanding of viral load; 95% CI: 1.50-11.52) and viral suppression (AOR: 2.75 for understanding of CD4 count; 95% CI: 1.31-5.80).

**Conclusion** This study highlights the importance of quality of care and treatment literacy on ART adherence and viral suppression. Programmatic investments should aim to promote treatment education, ensure effective and respectful patient-provider communication while promoting an environment of care with dignity, and address the costs associated with HIV care that continue to limit the ability of FSWs to optimally navigate through the HIV care continuum.

**Key words:** Latin America and the Caribbean, sex work, cisgender female sex workers, HIV, care continuum, treatment literacy

## Introduction

Female sex workers (FSWs) are among the most marginalized populations experiencing stigmatization, discrimination and violence, among other human rights violations, which serve to elevate their susceptibility to HIV and other sexually transmitted infections (STI).[1-10] Evidence suggests substantially higher levels of HIV among FSWs compared to women of reproductive age overall across all geographic settings.[1,2,6,11-17] In the Dominican Republic (DR), global trends surrounding FSWs and HIV are reflected across the country where FSWs have nearly 5 times greater odds to be living with HIV compared to other adults (HIV prevalence of 4.4%[9] vs. 0.9%[18]).

The continued focus on antiretroviral therapy (ART) based prevention, aiming to expand the use of ART as both a means to improve the individual health outcomes of people living with HIV (PLHIV) and to reduce the HIV incidence at the population level,[19,20] has further underscored the importance of assessing the care experiences of PLHIV, which could affect how PLHIV initiate and adhere to ART regimens. FSWs are among the key population groups for which ART-based prevention may have a particularly significant impact given their elevated burden of HIV compared to other adults and their important role in ongoing HIV transmission networks.[20,21] Nevertheless, the stigmatization of FSWs across socio-cultural contexts has limited their access to healthcare and other social services, thus creating a barrier for optimizing the use of ART among this population.[21,22] As a result, globally, it is estimated that only 38% of FSWs living with HIV report current ART use and among those 57% are virally suppressed.[20]

Understanding the experiences of FSWs as they navigate the HIV care continuum -defined as the steps ranging from HIV diagnosis, linkage to care, retention in care, ART adherence, and viral suppression[23]- is critical to address the contributing barriers and limitations in care leading to sub-optimal HIV outcomes and thus contributing to the ongoing transmission of HIV.[24] Studies have found that FSWs' experiences in the HIV care environment highly influence their HIV outcomes.[25-28] For example, in Tanzania, a qualitative study found that disrespectful and abusive treatment in the clinic environment was linked to missed HIV care appointments and disengagement in care.[28] In the DR, a study highlighted the effect that the healthcare system could have on FSWs' ability to remain adherent to ART, with positive patient-provider relationships found to be a protective factor against ART interruption.[27] In addition, a systematic review conducted utilizing data from Sub-Saharan Africa found that stigma and discrimination (related to the socio-structural context of sex work) from healthcare providers negatively affected the experiences of FSWs' linkage to care, retention in care and ART initiation.[26] Furthermore, despite some evidence underscoring the associations between treatment education among PLHIV and positive HIV outcomes,[29,30] there is limited understanding of the role of treatment literacy on HIV outcomes among FSWs.

In the DR, interventions have focused on helping FSWs navigate through the HIV care continuum,[8,9,27] and successful HIV diagnosis and linkage to HIV care have been observed among this group.[8] However, viral suppression remains a sub-optimal HIV outcome. An earlier study indicated that while 89% of FSWs reported being adherent to ART in the last 4 days, only 51% had an undetectable viral load post intervention efforts.[9] These results emphasize the need to address barriers and facilitators to HIV treatment and care within healthcare structures as

essential opportunities to improving the HIV outcomes and quality of life of FSWs. To date, an assessment between the quality of treatment and care services, FSWs' treatment literacy, and HIV outcomes, specifically biological outcomes like viral suppression, has been limited in the DR and other settings. This study aimed to quantitatively examine the relationship between the quality of care, treatment literacy, and HIV outcomes (ART adherence and viral suppression) among FSWs to inform future interventions in this area.

*Theoretical Orientation*

We first conceptualized the relationship between HIV quality of care with ART adherence and viral suppression by drawing from the Donabedian framework on quality assurance in health care.[31,32] The Donabedian framework posits that there are two types of domains contributing to the quality of care, which together affect the health outcomes experienced by individuals.[31,32] These two domains are known as *process of care* and *structure of care*. *Process of care* measures center on the relational aspects of the delivery of care (e.g., the relationship between patients and providers), and are defined as the activities that constitute the receipt of care.[31] Drawing from our qualitative work (See Chapter 5), factors that were important in the quality of care experience of FSWs as they navigated through HIV care included the patient-provider communication, ability for provider continuity of care as this aided in building more trusting patient-provider relationships, and treatment in the clinic environment. *Structure of care* measures are defined as the conditions under which care is rendered to patients.[31] Salient under this domain, supported by our qualitative work, was the associated HIV care cost for which FSWs were responsible for when assessing HIV treatment and care services. In addition, we seek to explore the type of HIV

care facility (public versus private) as a measure under this domain given some of the observed differences by type of care facility found in our previous work (See Chapter 5).

Lastly, evidence suggests the effect of health literacy as a critical component to empowering patients to advocate for their own health and address health outcomes.[33] Based on our qualitative work, we found that FSWs, through knowledge around treatment and the implications of treatment on biological outcomes (treatment literacy), were able to better advocate and exert greater control over their HIV treatment and care and potentially impact their HIV outcomes directly (See Chapter 5). As such, we recognized the role of treatment literacy in promoting *agency* among FSWs which could in turn have an effect on the quality of HIV care experienced and the resulting HIV outcomes. To this end, our model also draws from Gidden's Structuration Theory, which supports the contributing role that a person's own agency or sense of power has on their ability to influence their outcomes, to explore the relationship between treatment literacy on HIV outcomes of ART adherence and viral suppression.[34] **Figure 6-1** provides a graphical depiction of the conceptual framework guiding this work.

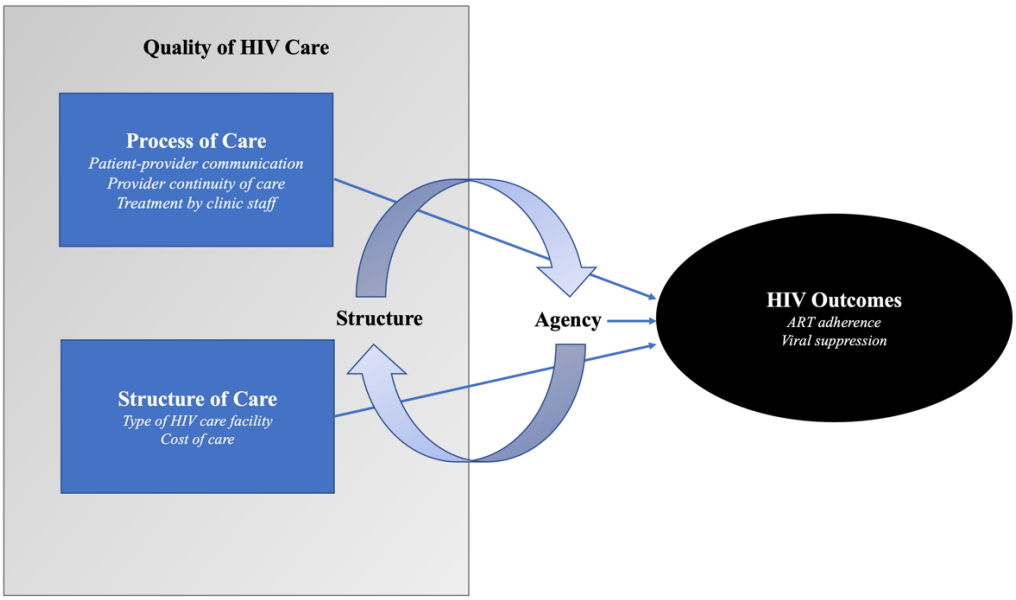


**Figure 6-1.** Conceptual framework

## Methods

### *Study Design*

This study is embedded within the NIMH-funded parent study "Stigma, cohesion and HIV outcomes among vulnerable women across epidemic settings" (R01MH110158), a longitudinal observational cohort study being conducted in Iringa, Tanzania and Santo Domingo, DR. The study aims to establish the role of socio-structural and behavioral factors along the pathway to viral suppression among FSWs living with HIV to inform tailored and effective HIV prevention, treatment and care programs. In each of these two settings, a cohort of approximately 200 FSWs living with HIV was enrolled and is being followed prospectively at 0, 12 and 24 months. The current study uses data from the second round of data collection (at 12 months) in the DR (n=211) collected between December 2018 and November 2019.

*Study Setting and Participants*

The DR cohort was based largely on an already established cohort of FSWs living with HIV through the *Abriendo Puertas* (Opening Doors) intervention.[8,9] Recruitment of study participants in the DR was further enhanced through the aid of peer navigators from the sex worker-rights group, MODEMU (*Movimiento de Mujeres Unidas*), key informants, and participants themselves. Eligibility criteria for participants included being at least 18 years of age, with a confirmed HIV-positive diagnosis, and having reported exchanging sex for money in the last month prior to enrollment. Women who did not meet the eligibility criteria or were unable to provide informed consent were excluded from the study. Women recruited for the study completed a socio-behavioral survey and blood was drawn for clinical laboratory tests at each study visit. In addition, participants' medical records were also reviewed as part of the longitudinal study.

*Data Collection Procedures and Measures*

Data collection was conducted by the IDCP (*Instituto Dermatológico y Cirugía de Piel Dr. Huberto Bogaert Díaz*) in Santo Domingo, DR. Surveys were administered by experienced interviewers utilizing a tablet in a private location at a time most convenient for study participants. Prior to administering the survey, interviewers collected informed consent from each participant, and for participants with a non-confirmed HIV diagnosis, a rapid test was administered to confirm HIV status. The survey examined a range of topics, including: demographic and occupational characteristics, experience with HIV and sex work related stigma, provider communication and dynamics, satisfaction with clinic and HIV related services, experience with peer navigation, experience with ART stigma and ART adherence. During each

survey visit, participants who provided informed consent also participated in a blood draw (of 10 mL) done by the IDCP laboratory team. The IDCP laboratory team then used the 10 mL of blood to create three 1.8 mL plasma aliquots, which were stored at -80ºC and then shipped using the appropriate laboratory procedures. For viral load, the testing took place at the National Dominican Reference Laboratory. HIV viral load testing was assessed using polymerase chain reaction (PCR) technology with the Roche Amplicor HIV-1 Monitor Test. In addition, supported by informed consent, a medical chart review was also conducted for all participants enrolled in the parent study.

*HIV outcome measures.* Self-reported ART adherence was measured by investigating participants ART adherence over the past 4 days. In particular, participants were asked on how many of the past 4 days they have missed taking their ART medication, with answers for this question ranging from none to 4 days. Responses for this question were dichotomized with "0" indicating no ART adherence in the last 4 days, and "1" indicating adherence to ART in each of the last 4 days. The measure of viral suppression was created based on participant's viral load. Participants with less than 400 copies/mL were coded as being virally suppressed, while participants with viral loads of 400 or more copies/mL were classified as not being virally suppressed.

*Individual measures.* Participants' *treatment literacy* was assessed through two questions inquiring about viral load and CD4 count and how these two biological measures relate to their HIV treatment. Participants were asked if the goal of treatment is to make viral load go up or down, and if the goal of treatment is to make the CD4 count go up or down. Participants who

responded correctly to viral load (the goal of treatment is to make viral load go down) were coded as having an understanding of viral load as it relates to their treatment plan. Participants who responded correctly to CD4 count (the goal of treatment is to make CD4 count go up) were coded as having an understanding of CD4 count as it relates to their treatment plan. Other individual level characteristics included participants' age and educational attainment.

*Process of care measures.* Sex work disclosure to healthcare providers was assessed through a question in which participants were asked if their healthcare provider had asked about their sex work occupation, and answers for this question were captured as yes or no. Patient-provider communication and trust was assessed through Galassi's 15-item validated scale on Patient Reactions Assessment (PRA).[35] PRA provides a measure for the perceived quality of the information given by the provider, affective behaviors of the provider, and patient's perceived ability to communicate with the provider.[35] Cronbach's alpha was used to assessed the internal consistency, or reliability, with a value of 0.80 or higher indicating that the scale has good internal consistency.[36,37] The PRA scale has been used in previous studies working with FSWs living with HIV in the DR,[27,38] and was found to have a good reliability with a Cronbach's alpha of 0.80. Continuity of care was assessed through a survey question asking participants if they are seen by the same provider during each HIV care visit. Treatment by clinic staff was measured using a survey item assessing patient interaction with clinic staff. This item measured feeling respected by clinic staff with answers on an ordinal scale ranging from 1=always to 4=rarely or never. This measure was dichotomized to indicate always being respected versus not always feeling respected by clinic staff.

*Structure of care measures.* Based on survey responses to questions about location where participants obtain their HIV care, and confirmed through medical chart review, we developed a variable on type of medical facility where the participant receives care, with options of care facility being either a public or private HIV comprehensive care service site. Cost of care was developed utilizing an index of different type of items associated with HIV care costs. These items included any payments or fees made as part of the HIV care visit, any additional medication costs incurred during the HIV care visit (this item excluded ART costs as ART is provided free of charge in the DR[39]), any costs associated with transportation to clinic appointments, any costs associated with food intake during the HIV care visit, any costs associated with childcare incurred due to the HIV care visit, and any loss of income due to the HIV care visit. These associated HIV care costs were totaled and split around the median for the purpose of analysis.

*Statistical Analysis*

We first began to explore the data from round two by conducting exploratory data analysis on key variables of the survey data. Specifically, we examined the distributions of continuous variables noting particular parameters such as the mean, median, standard deviation, interquartile range (IQR) and range. Categorical variables were assessed through the use of frequencies and proportions. Visual descriptions (not shown in paper) of the variables were examined through the use of histograms and box-plots in an effort to understand the distribution of the different measures. Associations between the two HIV outcomes of interest, ART adherence and viral suppression, were explored through a Chi-Squares test and a simple logistic regression. Regarding model selection, variables included in the model were selected informed by the

qualitative data analysis on the most pertinent measures that affect the dynamics of quality of HIV care among FSWs (See Chapter 5). As such, the model was built under the hypothesis that both measures of process of care and structure of care, along with individual measures that examine agency via treatment literacy, would be associated with ART adherence and viral suppression. For each outcome, we explored these associations utilizing a random-effects multivariable logistic regression in order to account for potential intra-cluster correlations among FSWs who access HIV care from the same HIV care facility. A total of 11 different public and private clinics were documented for our sample. Results from these random-effects multivariable logistic regressions are expressed in terms of adjusted odds ratio (AOR) and 95% confidence intervals (CI). We imputed data on 18 observations collected during round two that had missing information on select questions assessing their clinic level care utilizing participant data from round one. Sensitivity analyses indicate that the models presented in these results were not affected by these imputations, as results changed only marginally and the main conclusions of the paper hold. All analyses were conducted using the quantitative software Stata SE version 15.1.[40]

*Ethical considerations*

This study received human subjects research approvals from the Institutional Review Boards (IRBs) of the Johns Hopkins University Bloomberg School of Public Health (Baltimore, MD), and from IDCP *Unidad de Vacunas e Investigación* and the *Consejo Nacional de Bioética en Salud* (CONABIOS) (Santo Domingo, DR). All participants in the study received 400 Dominican pesos (approximately $7 U.S. Dollars) compensation for their time during each study visit.

## Results

*Participant Characteristics*

**Table 6-1** presents the sociodemographic and occupational characteristics of participants included the study. Among the sample of 211 female sex workers (FSWs), the median age was 41 years (interquartile range [IQR]: 35- 46 years old) at the time of the interview. Most FSWs in the sample had low educational attainment, having completed only primary school or less (61.1%), and most women were living without a partner (58.8%). The vast majority were mothers (94.3%) with a median number of children of 3 (IQR: 2-4 children). The median number of years involved in sex work was 19 (IQR: 12-26 years), and 73.0% of participants had disclosed their sex work occupation to their personal network. Most participants reported not traveling outside Santo Domingo for sex work in the past 6 months (84.8%), and the median average number of clients per week over the past six months was reported to be 3 clients (IQR: 2-4 clients per week). Most participants self-identified as heads of household (75.4%), and sex work contributed to 75.0% of their personal monthly income (IQR: 46.5%-100.0%), which had a median of 8,000 Dominican Pesos or approximately $137 U.S. Dollars (IQR: 5,000-14,000 Dominican Pesos). 13.3% of participants reported experiencing any gender-based violence in the past 6 months, and 34.6% of participants reported either never or rarely drinking while working to meet clients.

**Table 6-1.** Sociodemographic and occupational characteristics for female sex workers living with HIV (n=211)

| | n | % |
|---|---|---|
| ***Sociodemographic Characteristics*** | | |
| Age (median, IQR) | 41 | (35, 46) |
| Education | | |
| Primary or less | 129 | 61.1 |
| Secondary or More | 82 | 38.9 |
| Relationship Status | | |
| Without a partner | 124 | 58.8 |
| With a partner | 87 | 41.2 |
| Number of children (median, IQR) | 3 | (2, 4) |
| ***Occupational Characteristics and Risk Factors*** | | |
| Years in sex work^ (median, IQR) | 19 | (12, 26) |
| Disclosure of sex work occupation to personal network | | |
| No | 57 | 27.0 |
| Yes | 154 | 73.0 |
| Travel outside Santo Domingo due to sex work in past 6 months | | |
| No | 179 | 84.8 |
| Yes | 32 | 15.2 |
| Average number of clients per week | 3 | (2, 4) |
| Head of household | | |
| No | 52 | 24.6 |
| Yes | 159 | 75.4 |
| Average personal monthly income in Dominican Pesos (median, IQR) | 8,000 | (5,000, 14,000) |
| Proportion (%) of personal income attributed to sex work (median, IQR) | 75 | (46.5, 100.0) |
| Experience any GBV in the past 6 months | | |
| No | 183 | 86.7 |
| Yes | 28 | 13.3 |
| Substance use while working to meet clients | | |
| Never | 39 | 18.5 |
| Rarely | 34 | 16.1 |
| Sometimes | 65 | 30.8 |
| Almost always | 31 | 14.7 |
| Always | 42 | 19.9 |

^ n=210

*HIV Treatment and Care*

The median number of years participants have been living with HIV was approximately 9 years and 2 months (IQR: 5.1-13.7 years), as shown in **Table 6-2**. The vast majority of participants had

engaged with HIV care, with 99.5% of participants reporting receiving some type of HIV medical or clinical care. When asked if HIV care had been received in the past 6 months, excluding medication pick up, 41.7% reported receiving HIV care at least once during this period. Furthermore, 31.0% reported missing an HIV care appointment in the past 6 months. Nearly all participants (97.6%) reported initiating ART, and the median time participants had spent on ART was approximately 6 years and 10 months (IQR: 3.0-10.6 years). At ART initiation, participants' medical charts revealed that the median viral load was 4,063 copies/mL (IQR: 50-58,853 copies/mL) while the median CD4 count was 309 cells/mm$^3$ (IQR: 155-543 cells/mm$^3$). Among the participants reporting to be currently on ART (96.2%), only 79.3% reported being adherent to their ART regimen during the past 4 days. Biological tests revealed that 76.2% of participants were virally suppressed (less than 400 copies/mL).

**Table 6-2.** HIV characteristics and outcomes of female sex workers living with HIV (n=211)

| | **n** | **%** |
|---|---|---|
| ***HIV Related Characteristics*** | | |
| Number of years living with HIV (median, IQR) | 9.2 | (5.1, 13.7) |
| Reported receiving any HIV medical or clinical care | | |
| No | 1 | 0.5 |
| Yes | 210 | 99.5 |
| Reported receiving HIV care in the past 6 months (exclude medical refill) | | |
| No HIV care | 123 | 58.3 |
| 1 time or more | 88 | 41.7 |
| Missed HIV care appointments in the past 6 months | | |
| No | 127 | 69.0 |
| Yes | 57 | 31.0 |
| Reported ever starting ART | | |
| No | 5 | 2.4 |
| Yes | 206 | 97.6 |
| Viral load at ART initiation (copies/mL) (median, IQR) ^ | 4,063 | (50, 58,853) |
| CD4 at ART initiation (cells/mm$^3$) (median, IQR) ^^ | 309 | (155, 543) |
| Number of years since ART initiation (median, IQR) ^^^ | 6.8 | (3.0, 10.6) |
| Currently on ART | | |
| No | 8 | 3.8 |
| Yes | 203 | 96.2 |

| | | |
|---|---|---|
| ***HIV Outcomes*** | | |
| ART Adherence in the past 4 days | | |
| No | 42 | 20.7 |
| Yes | 161 | 79.3 |
| Viral suppression (<400 copies/mL) | | |
| Not suppressed | 50 | 23.8 |
| Virally suppressed (<400 copies/mL) | 160 | 76.2 |

^n=183; ^^n=198; ^^^n=206

*Process and Structure of Care*

**Table 6-3** presents descriptive measures associated with participants' HIV care experience. When assessing participants' treatment literacy, 86.7% correctly reported the intent of treatment is to decrease their viral load. In addition, 81.5% of participants correctly reported how treatment is intended to increase their CD4 count. Regarding measures related to the process of care experienced by participants, less than half of participants (42.7%) reported ever being asked by their health care providers if they exchanged sex for money. In addition, the median patient-provider communication score was 45, with 14.4% of participants scoring above the median (results not shown). Over half of the participants reported not being seen by the same provider during each visit (52.5%). Most participants (91.1%) reported always being treated with respect at their HIV care facility when assessing care. When exploring structure of care measures, nearly half of participants (50.2%) reported receiving care from a public HIV care facility. In addition, when asked about the costs associated per HIV care visit, less than half of the participants (45.5%) reported spending over 400 Dominican Pesos (approximately $7 U.S. Dollars) per visit. As shown in **Figure 6-2**, among participants who incurred expenses due to their HIV care visits, most associated HIV care costs were related to transportation (34%), foregone income (33%), and food (24%) expenditures. Other contributions to the associated HIV care costs included childcare (4%), expenses for other medication (4%), and clinic fees (1%).

**Table 6-3.** Treatment literacy, and process and structure of care measures among FSWs living with HIV (n=211)

| | n | % |
|---|---|---|
| ***Individual Factors*** | | |
| *Treatment Literacy* | | |
| Is the goal of treatment to make the viral load go up or down? | | |
| Up | 28 | 13.3 |
| Down | 183 | 86.7 |
| Is the goal of treatment to make the CD4 count go up or down? | | |
| Down | 39 | 18.5 |
| Up | 172 | 81.5 |
| ***Process of Care*** | | |
| Has a health care worker ever asked you if you exchange sex for money? | | |
| No | 121 | 57.4 |
| Yes | 90 | 42.7 |
| Total Patient-provider communication score (PRA scale) (median, IQR) ^ | 45 | (44, 45) |
| Continuity of Care: Participant receives care from the same provider^ | | |
| No | 106 | 52.5 |
| Yes | 96 | 47.5 |
| The staff at the clinic where you get your HIV care always treats you with respect^ | | |
| No | 18 | 8.9 |
| Yes | 184 | 91.1 |
| ***Structure of Care*** | | |
| Type of Facility^^ | | |
| Private | 105 | 50.2 |
| Public | 104 | 49.8 |
| HIV care associated cost in Dominican Pesos^ | | |
| 400 pesos or less | 110 | 54.5 |
| Over 400 pesos | 92 | 45.5 |

^n=202; ^^n=209

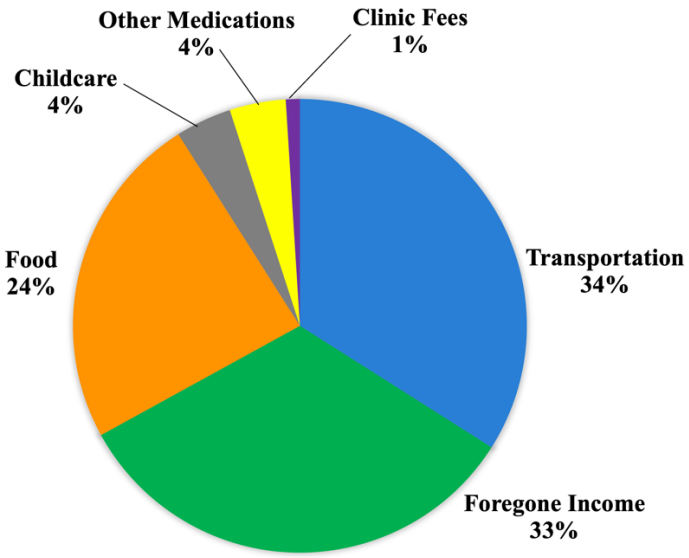


**Figure 6-2.** Distribution of associated HIV care costs

*Associations between Process and Structures of Care with ART Adherence and Viral Suppression*

The data uncovers a significant association ($X^2$=9.66, p<0.01) between ART adherence and viral suppression, as shown in **Table 6-4**. Specifically, a large proportion of participants who are not virally suppressed also report a lack of ART adherence (37.2%). Furthermore, participants who are adherent to ART have over 3 times the odds of being virally suppressed compared to participants who are not adherent to ART (OR: 3.31, 95% CI: 2.60 - 4.21) (data not shown in table).

**Table 6-4.** Associations between ART Adherence and Viral Suppression

| | Viral Suppression | | | | |
|---|---|---|---|---|---|
| | No (n=43) | | Yes (n=159) | | Chi² Statistics |
| | n | % | n | % | |
| *ART Adherence* | | | | | |
| No | 16 | 37.2 | 25 | 15.7 | 9.66** |
| Yes | 27 | 62.8 | 134 | 84.3 | |

** p<0.01

We conducted further assessments to understand the associations between the aforementioned process and structure of HIV care measures, and ART adherence and viral suppression while controlling for a select number of individual characteristics. As shown in **Table 6-5**, results revealed the convergence and divergence of the associations between the select number of factors on the two outcomes. The multivariable logistic regression model exploring associations with ART adherence revealed that the odds of being ART adherent increase with age (AOR: 1.07, 95% C.I.: 1.02 - 1.12). Results from this model also uncovered the significant association of treatment literacy on ART adherence. Participants who have the correct understanding of viral load had 4.15 times greater odds (95% CI: 1.50 - 11.52) of being adherent to their ART compared to those who lack understanding of viral load. Furthermore, though marginally significant ($p<0.10$), participants who have the correct understanding of CD4 count had nearly 2 times greater odds (95% CI: 0.98 - 3.78) of being adherent to their ART compared to those who lack understanding of CD4 count. In addition, HIV care costs were associated with decreased odds of ART adherence. For participants paying above 400 Dominican pesos, the odds of being adherent to ART are reduced by approximately 63% compared to those paying 400 Dominican pesos or less (AOR: 0.37, 95% CI: 0.23 - 0.60).

Results from the multivariable logistic regression model assessing the association between the process and structure of HIV care measures and viral suppression revealed similar findings. As observed in **Table 6-5**, there is a significant relationship between treatment literacy and viral suppression. Participants who reported understanding CD4 count had almost 3 times the odds of being virally suppressed compared to those who lacked understanding (AOR: 2.75, 95% CI: 1.31 – 5.80). In addition, participants' perceptions of the patient-provider communication were also

positively associated with being virally suppressed, with the odds of being virally suppressed increasing by 1.04 (95% CI: 1.01 - 1.07) for every unit increase in the patient-provider communication score. Moreover, participants who reported always being treated with respect in their health care environment had slightly over 2 times the odds of being virally suppressed compared to those not reporting always being treated with respect at their clinics (AOR: 2.17, 95% CI: 1.09 - 4.32). Participants who reported being asked by their provider about their sex work occupation had approximately 2 times the odds of being virally suppressed compared to those reporting not being asked by their provider of their sex work occupation, though this finding was only marginally significant (95% CI: 0.92 - 4.65; $p<0.10$). Continuity of care was negatively associated with being virally suppressed, with participants who received care from the same provider during each visit having odds of being virally suppressed reduced by 43% compared to those not being seen by the same provider during care visits (AOR: 0.57, 95% CI: 0.34 - 0.95). Similar to findings on the associations between cost of HIV care and ART adherence, the associated cost of HIV care was also negatively associated to being virally suppressed. For participants paying above 400 Dominican pesos, the odds of being virally suppressed are reduced by approximately 41% compared to those paying 400 Dominican pesos or less (AOR: 0.59, 95% CI: 0.41 - 0.85).

**Table 6-5.** Associations between treatment literacy, and process and structures of care with ART adherence and viral suppression

| | ART Adherence | | Viral Suppression | |
|---|---|---|---|---|
| | **AOR** | **95% Confidence Interval** | **AOR** | **95% Confidence Interval** |
| ***Individual Characteristics*** | | | | |
| Age | 1.07** | 1.02 - 1.12 | 1.03 | 0.99 - 1.07 |
| Educational attainment of primary or less | 1.58 | 0.64 - 3.86 | 1.47 | 0.94 - 2.30 |
| *Treatment Literacy* | | | | |
| Understands viral load | 4.15** | 1.50 - 11.52 | 0.79 | 0.33 - 1.93 |
| Understands CD4 count | 1.93 | 0.98 - 3.78 | 2.75** | 1.31 - 5.80 |
| ***Process of Care*** | | | | |
| Provider has asked about sex work | 1.71 | 0.63 - 4.60 | 2.06 | 0.90 - 4.72 |
| Patient-provider communication score (PRA scale) | 1.01 | 0.95 - 1.08 | 1.04* | 1.01 - 1.07 |
| Continuity of care: Patient sees the same provider at each visit | 0.56 | 0.26 - 1.18 | 0.57* | 0.34 - 0.95 |
| The staff at the clinic where you get your HIV care always treats you with respect. | 0.96 | 0.28 - 3.28 | 2.17* | 1.09 - 4.32 |
| ***Structure of Care*** | | | | |
| Public Facility | 0.65 | 0.37 - 1.14 | 1.33 | 0.94 - 1.89 |
| Associated cost of HIV care above 400 pesos per visit | 0.37** | 0.23 - 0.60 | 0.59** | 0.41 - 0.85 |
| *Random Effects* | | | | |
| Rho | 1.42E-07 | | 3.86E-11 | |
| *Model Diagnostics* | | | | |
| Log-likelihood | -85.57 | | -101.84 | |
| Wald $Chi^2(10)$; $p > Chi^2$ | 19653.88; <0.001 | | 4162.51; <0.001 | |
| Observations | 195 | | 200 | |
| Clusters (health facilities) | 11 | | 11 | |

Confidence intervals calculated based on robust standard errors.
** p<0.01, * p<0.05

## Discussion

To our knowledge, this study represents the first quantitative work aiming to understand the relationship between quality of care and treatment literacy on ART adherence and viral

suppression among FSWs. This study presents a significant contribution to the HIV treatment and care literature as it highlights three relevant areas where program efforts could be targeted to ensure ART adherence and viral suppression among this vulnerable group. These areas include: (1) at the individual level: improving HIV treatment literacy; (2) at the process of care level: promoting efforts to deliver care with dignity and respect while also encouraging effective practices for patient-provider communication; and (3) at the structure of care level: addressing out of pocket costs associated with HIV care. In particular, in light of the global community call to action to end the HIV epidemic as a public health threat by 2030,[41-44] and attain the 95-95-95 HIV targets,[44] these three key areas provide a pathway forward for programmatic efforts targeting vulnerable groups affected by the HIV epidemic.

Studies have found the need for promotion efforts of HIV treatment literacy among PLHIV.[29,30] As highlighted in our results, this is a program area that could effectively aid in achieving ART adherence and viral suppression. In our study, FSWs who have an understanding of viral load were more likely to report adherence to their ART regimens; whereas FSWs who reported an understanding of CD4 count where more likely to be virally suppressed. Given the reported associations between ART adherence and viral suppression, these findings exacerbate the need to support efforts to improve treatment literacy, with a particular focus on engaging with patients to encourage a clear understanding of the effect of HIV treatment on viral load and CD4 count. PLHIV want to be involved in decisions about their treatment and care,[45] thus promoting treatment literacy could be one of the first steps in getting patients involved in their care. Promoting an understanding of these concepts will not only aid in achieving optimal HIV

outcomes, but will also enhance patients' own sense of power (their agency) and their contributing role in treating their disease and achieving an undetectable viral load.

Our study also underscores the need to focus on the patient-provider and patient-clinic dynamics, as our results revealed the direct effect that these relationships have in promoting viral suppression. In particular, participants in our study who reported better patient-provider communication and reported always being treated with respect at the clinic where they receive their HIV care were more likely to be virally suppressed. These findings emphasize the need for sensitivity trainings for healthcare providers and clinic staff to promote techniques to aid in conveying medical information respectfully, effectively, and with understanding of the needs for PLHIV and in particular those engaging in sex work. This has been an important area of work that has been stressed by other studies,[3,27,46] and one that continues to impact achieving positive HIV outcomes. Encouraging effective patient-provider communication could also aid in increasing patients' treatment literacy and in providing high quality information to patients- a key aspect sought out by PLHIV in the delivery of care.[45] Effective communication should be promoted in healthcare settings given direct associations to positive HIV outcomes. For example, one study assessing effective patient-provider communication found that patients were significantly more likely to adhere to ART when providers discussed adherence issues that patients may be facing, the impact of lack of adherence on medications losing effectiveness, and understanding HIV drug resistance.[47]

Continuity of care has also been an aspect that is highly valued by PLHIV,[45] and in our qualitative work we also observed participants' desire to receive HIV care from the same

provider during each care visit as a mechanism for FSWs to build trusting relationships with their providers (See Chapter 5). Nevertheless, in our study, we found a negative association between continuity of care and viral suppression. In fact, our results highlighted that participants who obtained HIV care from the same provider were less likely to be virally suppressed. Drawing from our qualitative work, we hypothesize that participants who lack continuity of care have exercised a higher degree of agency and are subsequently more involved in the decisions surrounding their treatment and care given their inability to build trusting relationships with their healthcare providers due to provider mobility. In effect, the lack of trust in providers has led to higher control over FSWs' treatment and care decisions (See Chapter 5).

Lastly, addressing the out-of-pocket associated costs of HIV care by both acknowledging their impediment to achieving optimal HIV outcomes and providing pathways to remediate the negative effect that these costs of care have on HIV outcomes is imperative as we continue to strive to provide more equitable care to FSWs living with HIV. Despite the provision of HIV treatment at no cost in the DR,[39] our results highlight the direct negative effect that high costs associated with HIV care have on not only ART adherence but also viral suppression. As such, this underscores the importance of addressing cost limitations beyond the costs associated with ART on the successful achievement of optimal HIV outcomes among FSWs. Participants who reported paying above 400 Dominican Pesos (~approximately $7 US Dollars) per visit have lower odds of not only being adherent to ART, but also of being virally suppressed. Given FSWs' financial insecurity,[48,49] addressing these costs is critical to increasing positive HIV outcomes among this group. A study exploring out-of-pocket costs associated with HIV care, found the regressivity effects of cost of care, with lower income earners having an increased

burden of higher out-of-pocket costs.[39] This highlights the need to further the dialogue on strategies to support PLHIV, especially those who are low-income earners or with unreliable work wages such as FSWs. In our study, most associated HIV care costs incurred by participants derived from transportation, food, and foregone income. As recognized by Chaumont and colleagues, ensuring that government agencies and civil society organizations include the impact that out-of-pocket expenses related to HIV care are part of the conversation[39] could serve to begin working on action plans to start exploring how to address the financial burden experienced by PLHIV and the direct effect of this financial burden on deterring from achieving optimal HIV outcomes. In addition, voucher strategies, such as financial incentives for transportation and food, should be explored as a strategy to address the financial vulnerability that is experienced by FSWs when accessing HIV care. This strategy has been found effective in other settings among PLHIV, where incentives for food support were associated with ART initiation[50] while financial incentives, in the form of quarterly gift cards, were associated with viral suppression.[51]

This study is not without limitations. First, it is important to acknowledge that our sampling strategy has its biases. FSWs in our study had to have disclosed at least to one person their HIV status (e.g., the study recruiter, peer navigator), and as such, this is a sample of FSWs that are likely to be more aware of their HIV status and in turn potentially have a greater likelihood to engage in care. Nevertheless, research conducted by the parent study team continues to highlight that despite high linkages to care among this population, FSWs living with HIV in the DR continue to experience sub-optimal HIV outcomes such as sub-optimal levels of viral suppression.[8,9] This underlines the need for the current work as it provided further insight into the contributing role that quality of care and treatment literacy have on positive HIV outcomes

among this population. Second, the study relies on data collected at round two. This presents a study limitation given the cross-sectional nature of the study limits our ability to draw causal inferences about the relationships between quality of care and treatment literacy on ART adherence and viral suppression. Lastly, there is the potential of recall bias regarding cost variables, which could affect the precision of this variable.

This study highlights the importance of quality of care and treatment literacy in achieving optimal HIV outcomes among FSWs. Results from our study underscore three areas that affect ART adherence and viral suppression, which include treatment literacy, patient-provider and patient-clinic dynamics, and associated cost of HIV care. Program and investment efforts should be made to promote FSWs' understanding of their HIV treatment, further train providers to deliver HIV care to FSWs with dignity and respect, and to address the financial burden experienced by FSWs due to HIV care and the impact that this has on achieving ART adherence and viral suppression.

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## Chapter 7: "Por ella estoy viva": Exploring the role of peer navigation and support in the quality of HIV care experiences of female sex workers living in the Dominican Republic (Manuscript 3)


### Abstract

**Background:** Despite evidence on peer navigation's association on positive HIV outcomes, such as engagement in HIV care and ART initiation, the mechanisms through which peer navigation may influence these outcomes have been less explored. The purpose of this study is to describe the role of peer navigation and support on enhancing the quality of HIV care experienced by female sex workers (FSWs).

**Methods:** Data was derived from a quantitative cohort (n=211) of FSWs living in the Dominican Republic, and complemented with data from two rounds of in-depth interviews (IDIs) from a qualitative subsample (n=20 per round). Descriptive statistics and multivariable logistic regressions were used to explore the association of peer navigation with relational aspects of care and satisfaction of the quality of HIV treatment and care. Thematic analysis was employed to code and synthesize textual data from IDIs.

**Results:** 41.2% of the participants reported having had contact with a peer navigator in the last 6 months. Qualitative data revealed that peer navigation and support was instrumental in assisting FSWs link to HIV care after diagnosis, encouraging FSWs' ability to access more comprehensive clinical care facilities, and promoting agency by improving FSWs' skills to more strategically and effectively engage with the clinic environment and health care providers. Peer navigation was positively associated with experiencing more respectful treatment by clinic staff (AOR: 6.65, 95% CI: 2.32-19.02), and greater satisfaction with overall HIV care services (AOR:

2.57, 95% CI: 1.77-3.74). Integration of peer navigation into HIV care was recommended as a strategy by FSWs for improving their experience in the HIV care environment.

**Conclusion:** Promoting the full integration of peer navigation into healthcare structures is a strategic approach towards improving the quality of HIV care experienced by FSWs.

**Key Words:** HIV care continuum, cisgender female sex workers, peer navigation, quality of care

## Introduction

Peer navigation has been shown to be an important strategy to improve the quality of HIV treatment and care, including within efforts to enhance engagement and retention in care and support ART initiation and adherence among people living with HIV (PLHIV).[1-6] Through peer navigation, PLHIV are often better able to harness support to more effectively navigate through the HIV care continuum, often housed in complex and fragmented healthcare structures.[4]

Studies have highlighted the variations in the roles, responsibilities and level of engagement of peer navigators within HIV treatment and care services.[4,6,7] Despite the variability in the implementation of peer navigation services, what is less variable is the effect of peer navigation across diverse populations and settings, as peer navigation has been found to be instrumental in addressing the HIV epidemic and improving the quality of life for PLHIV. For example, in South Africa, the use of peer navigators facilitated greater engagement in HIV care, ART adherence and enhance HIV prevention practices by helping participants overcome self-stigmatizing views about their HIV status which often prevented them from accessing care.[1] This study also found that using individuals that could relate to patients through their lived experiences aids in fostering a trusting environment through rapport while providing patients with an example of how to model behavior to reach optimal HIV outcomes.[1] Another study conducted in the United States found significant associations between peer navigation and preventing declines in viral suppression.[2] In the Dominican Republic (DR), a qualitative study found that men who have sex with men (MSM) and female sex workers (FSWs) highly support the use of their peers to navigate the HIV care environment as these individuals not only imparted instrumental

knowledge about HIV and treatment, but also treated participants with respect.[8] Another study from the DR revealed the pivotal role of peer navigation through the implementation of a multi-level intervention.[3,9] In this study, peer navigation was established to bring forth support and accompaniment to FSWs living with HIV, while also advocating for them.[3,9] Results from this study found that peer navigation, along with individual counseling, sensitivity trainings for clinicians and a community mobilization strategy, improve ART adherence and consistent condom use among FSWs living with HIV.[9] Despite research surrounding the associations between peer navigation and HIV care outcomes, more evidence is needed to understand the mechanisms or pathways through which peer navigation influences HIV outcomes. Specifically, given findings on the critical role of clinic and provider dynamics on FSWs' engagement in care, ART initiation and ART interruption,[10-13] it is important to explore the influence that peer navigators may have in the quality of HIV care of FSWs as they progress through the HIV care continuum.

Given the recognition of peer navigation as a key strategic recommendation to meet UNAIDS 95-95-95 HIV epidemic goals by 2030,[7,14] uncovering the pathways through which it influences the experiences of key populations, like FSWs, as they navigate through HIV care is essential as continued investments are being made to promote effective HIV prevention, treatment and care programs. Globally FSWs are among the most vulnerable populations experiencing disproportionate burden of HIV,[3,9,15-22] with FSWs between the ages 15 and 49 years having 13.5 times greater odds to be living with HIV compared to women of reproductive age overall in low- and middle-income countries.[23,24] In the DR, FSWs continue to be a key population being targeted in HIV prevention efforts as FSWs are nearly 5 times more likely to be living with HIV

compared to other adults (HIV prevalence of 4.4%[9] vs. 0.9%).[25] Despite programmatic and intervention efforts, in the DR, the HIV epidemic goals continue to remain sub-optimal, with data suggesting that as of 2019 88% of PLHIV know their HIV status, 48% are receiving ART continuously, and 40% are virally suppressed.[26] Recommendations to address the HIV epidemic in the DR focus on targeting key populations, including FSWs, and integrating intervention and practices that foster their engagement and retention in care and ultimately reaching viral suppression, while also recognizing the importance of strengthening anti-discriminatory practices that continue to permeate healthcare structures.[26]

The purpose of this study is to describe the role of peer navigation and support on enhancing the quality of HIV treatment and care services experienced by FSWs. We aimed to explore this by (1) exploring the associations of peer navigation and overall satisfaction with HIV services and positive relational aspects of quality of HIV care, in particular improving patient-provider communication and respectful treatment by clinic staff; and (2) providing a more nuanced description of the level and type of engagement of FSWs with peer navigation and support as they engage with HIV treatment and care services by integrating qualitative and quantitative methodologies.

*Theoretical orientation*

We conceptualized the role of peer navigation by drawing from Freire's theory of critical consciousness[27,28] to understand the effect that peer navigation may have on supporting the quality of HIV care received by FSWs. Freire's theory on critical consciousness argues that people are often not aware of structural inequalities and as such cannot take the appropriate steps

to combat oppressive systems that continue to perpetuate their inequality.[27-29] Freire maintained that it is important for people experiencing inequality due to oppressive norms and structures to "think critically about oppressive realities and challenge inequitable social conditions to reclaim their humanity."[29] One method of achieving this is by generating a space for critical consciousness to grow through practices wherein people could become aware of their inequality through community empowerment strategies,[30] such as through the use of peer navigation and support.[31]

Among FSWs living with HIV, FSWs are exposed to a socio-cultural environment, which often limits their ability to navigate effectively through healthcare environments. FSWs often experience stigma and discrimination from the community and healthcare professionals,[21,26,32] in addition, to experiencing their own self-stigmatizing views, which is often inundated with feelings of shame.[21] Peer navigation and support could be a mechanism for combating these experiences and addressing the healthcare barriers that lead to suboptimal HIV outcomes among this population. For example, peer navigation provides an opportunity to focus on patients' own lived realities outside of the healthcare environment, and thus, provides an opportunity to better assess the barriers that patients may be encountering as they navigate through healthcare structures and propose opportunities to meet those demands.[31] In this paper, peer navigation and support are provided by current or former FSWs who have experience with HIV outreach, prevention, and support activities for people living with HIV. As such, we postulate that given peer navigators ability to provide culturally and linguistically appropriate assistance and support to FSWs living with HIV, while also challenging structural barriers within the healthcare system, peer navigation and support is a strategic approach to curtail the deficiencies within the

healthcare system (e.g., poor treatment and communication by clinical care staff), and thus, better facilitate the pathway to viral suppression among this population.

## Methods

### *Study Design and Parent Study Characteristics*

This study was embedded within the NIMH-funded parent study "Stigma, cohesion and HIV outcomes among vulnerable women across epidemic settings" (R01MH110158), a longitudinal observational cohort study being conducted in Iringa, Tanzania and Santo Domingo, DR. The parent study aims to improve the health of FSWs and reduce the ongoing transmission of HIV by establishing the role of socio-structural and behavioral factors along the pathway to viral suppression and informing tailored and effective HIV prevention, treatment and care programs. In each of these two settings, a cohort of approximately 200 FSWs living with HIV has been selected and is being followed prospectively at 0, 12 and 24 months. In addition, as part of the parent study, a subsample of 40 women (n=20 in Tanzania and n=20 in the DR) from the original cohort were invited to form part of a qualitative longitudinal cohort study aiming to explore the dynamic context of social cohesion and HIV and sex work related stigma among FSWs in relation to HIV services and outcomes. This qualitative cohort is being followed prospectively and will complete a total of three rounds of in-depth interviews, with each interview being conducted on a yearly basis starting in October 2018.

The current study draws from data from the second round of quantitative survey data collection (at 12 months) in the DR from the parent study, while also utilizing the first two rounds of in-depth interviews from the qualitative subsample in the DR.

*Study Setting and Participants*

The DR cohort was based largely on an already established cohort of FSWs living with HIV through the *Abriendo Puertas* (Opening Doors) intervention.[3,9] Recruitment of study participants was further enhanced through the assistance of peer navigators from the sex worker-rights group, MODEMU (*Movimiento de Mujeres Unidas*), key informants, and participants themselves. Eligibility criteria for participants included being at least 18 years of age, with a confirmed HIV-positive diagnosis, and having reported exchanging sex for money in the last month prior to enrollment. Women who did not meet the eligibility criteria or were unable to provide informed consent were excluded from the study. Women recruited for the study completed a socio-behavioral survey and blood was drawn for clinical laboratory tests at each study visit to assess HIV biological outcomes such as viral suppression.

*Data Collection and Measures*

The second round of data collection (at 12 months post baseline) in the DR (n=211) took place between December 2018 and November 2019. Data collection was conducted by the IDCP (*Instituto Dermatológico y Cirugía de Piel Dr. Huberto Bogaert Díaz*) in Santo Domingo, DR. Surveys were administered by experienced interviewers utilizing a tablet in a private location at a time most convenient for study participants. Prior to administering the survey, interviewers collected informed consent from each participant, and for participants with a non-confirmed HIV

diagnosis, a rapid test was administered to confirm HIV status. The survey examined a range of topics, including: demographic, occupational and HIV characteristics; patient-provider communication and dynamics; satisfaction with clinic and HIV related services; and experience with peer navigation.

*Relational Aspects of Quality of Care.* The survey was used to obtain two of the main outcomes of interest: patient-provider communication and respectful treatment by clinic staff in the HIV care environment. The patient-provider communication and trust was assessed through Galassi's 15-item validated scale on Patient Reactions Assessment (PRA).[33] PRA provides a measure for the perceived quality of the information given by the provider, affective behaviors of the provider and patient's perceived ability to communicate with the provider.[33] This measure has been used in previous studies working with FSWs living with HIV in the DR,[12,34] and was found to have good internal consistency,[35,36] or reliability, with a Cronbach's alpha of 0.80. Respectful treatment by clinic staff was measured using a survey item assessing patient interaction with the clinic staff where they receive their HIV care. Specifically, this item measured feeling respected by clinic staff with answers on an ordinal scale ranging from 1=always to 4=rarely or never. This measure was dichotomized to indicate always being respected versus not always feeling respected by clinic staff.

*Overall Satisfaction with HIV Care Services.* The last outcome of interest is overall satisfaction with HIV clinic services. Overall satisfaction with HIV care was assessed through a question inquiring participants' rating of the services at the clinic where they receive their HIV care, with answers ranging from 1=excellent to 5=weak. This variable was dichotomized to indicate a

rating of very good or excellent versus not very good or excellent. This measure on clinic satisfaction has been tested in this context (i.e., FSWs living with HIV in the DR) as part of the *Abriendo Puertas* program evaluation.[34]

*Peer Navigation.* The main independent variable of interest, peer navigation, was assessed utilizing 8 survey items, which have been previously included as part of the *Abriendo Puertas* intervention evaluation in the DR.[3,9] Participants were asked to report the level of engagement with peer navigators (including if they have had contact with peer navigators and frequency of contact). In addition, participants were also asked if peer navigators have provided accompaniment to HIV care appointments and other types of appointments outside of HIV care. Based on this information, we constructed a dichotomous measure to indicate whether or not participants have had any contact with a peer navigator in the past 6 months. Other variables related to peer navigation were used to provide a more nuanced description of the type and level of engagement participants reported having with a peer navigator.

*Statistical Analysis*

We first began exploring the data from round two by conducting exploratory data analysis on outcomes of interest, relational factors of quality of care and satisfaction with HIV care, and peer navigation measures. Other socio-demographic, occupational, and HIV related variables were also explored as part of the analysis. Distributions of continuous variables were assessed noting particular parameters such as the mean, median, standard deviation, interquartile range (IQR) and range. Categorical variables were assessed through the use of frequencies and proportions. Visual descriptions (not shown in paper) of the variables were examined through the use of

histograms and box-plots in an effort to understand the distribution of the different measures. Associations between the outcomes of interest, patient-provider communication, respectful treatment in HIV care environment and satisfactions with HIV services, and engagement with peer navigation were explored through Wilcoxon rank-sum and Chi-squares tests. Significant associations were then explored by utilizing random-effects multivariable logistic regressions. This type of regression was used in order to account for potential intra-cluster correlations among FSWs who access HIV care from the same facility. Within our sample (n=211), there was a total of 11 different public and private clinics. Results from random-effects multivariable logistic regressions are expressed in terms of adjusted odds ratio (AOR) and 95% confidence intervals (CI). All analyses were conducted using the quantitative software Stata SE version 15.1.[37]

*Qualitative Data Collection, Sample Characteristics and Analysis*

The qualitative subsample (n=20) was drawn from the main survey cohort from the DR utilizing a stratified purposeful sampling approach.[38] Using the existing data collected at baseline (at 0 months) participants were stratified into two groups: (1) participants who were virally suppressed (having less than 400 copies/mL) and (2) participants who were not virally suppressed (having 400 or more copies/mL). All 20 participants completed the first round of qualitative in-depth interviews between October and November 2018, while 18 participants completed the second round of qualitative in-depth interviews between December 2019 and January 2020. All in-depth interviews lasted approximately 60 minutes and were conducted in Spanish by two trained interviewers in a private office at the IDCP after securing informed consent.

All interviews were transcribed and analyzed in Spanish, and select quotes were translated to English for the purpose of manuscript development. Data analysis focused on capturing the experiences of FSWs with peer navigation and support as they coursed through HIV treatment and care services. We began our analysis by reading each transcript thoroughly prior to coding to allow for a deeper immersion into the contextual realities of each participant. Next, interviews were analyzed using a thematic analysis approach,[39] applying a combination of both inductive and deductive techniques. Freire's theory on critical consciousness[27,28] grounded the analytical process and provided a framework for what we expected to uncover in the analysis (for example, peer navigation/support and promoting agency). However, questions directly addressing the experiences with peer navigation and support were not included in the in-depth interview guides. As a result, many of the findings presented in this paper were based on emergent themes captured through the analytical exploration of the dynamics that contributed to the experience of quality of HIV care of FSWs. The findings presented were based on conversations wherein FSWs spontaneously spoke about their experience with peer navigation and support when addressing questions related to (1) first time linking to HIV care; (2) experiences with HIV treatment; (3) positive and negative experiences in the HIV clinic environment; and (4) recommendations for improving HIV care for FSWs. Throughout the coding and overall analytic processes, recurrent consultation with the research team allowed for a richer conceptualization and understanding of the findings surrounding peer navigation and support. Atlas.ti version 8.4.4[40] was used to managed the qualitative data.

*Ethical considerations*

This study received human subjects research approvals from the Institutional Review Boards (IRBs) of the Johns Hopkins University Bloomberg School of Public Health (Baltimore, MD), and from IDCP *Unidad de Vacunas e Investigación* and the *Consejo Nacional de Bioética en Salud* (CONABIOS) (Santo Domingo, DR). All participants in the study received 400 Dominican pesos (approximately $7 U.S. Dollars) compensation for their time during each study visit.

## Results

### *Sample Characteristics*

A total of 211 FSWs living with HIV participated in this study. Participants had a median age of 41 years (IQR: 35-46), most had an educational attainment of primary education or less (61.1%), less than half reported currently having a partner (41.2%), and the vast majority were mothers (94.3%). The median number of years of sex work reported by participants was 19 (IQR: 12-26), and 34.6% of participants reported always or almost always engaging in substance use (alcohol or drugs) while meeting clients. In addition, 13.3% of participants reported experiencing any gender-based violence in the past 6 months. Regarding FSWs' progress along the HIV care continuum, the vast majority of women reported ever engaging with HIV related medical or clinical care (99.5%), with most women also reporting currently being on an ART regimen (96.2%). Among participants reporting currently being on ART (n=203), 79.3% reported being adherent to their ART regimen in the past 4 days. Overall, 76.2% of participants in the study were virally suppressed (less than 400 copies/mL).

The sociodemographic characteristics of the qualitative subsample (n=20) did not vary significantly from the quantitative cohort. However, FSWs' progress along the HIV care continuum did vary from the quantitative cohort above. All FSWs in the qualitative subsample reported ever engaging with HIV related medical or clinical care, with 85.0% (n=17) of FSWs reporting currently being on an ART regimen. Among those FSWs currently on ART (n=17), the vast majority reported being adherent to ART in the past 4 days (15/17; 88.2%). Overall, 50.0% of participants in this subsample were virally suppressed.

*Engagement with Peer Navigation*

**Table 7-1** presents the results of FSWs' engagement with peer navigation. Less than half of FSWs (41.2%) reported coming in contact with a peer navigator about HIV related services and care in the past 6 months. Among participants who reported having any contact with a peer navigator, 68.3% of participants had in person contact with a peer navigator between 1 to 5 times in the past 6 months, whereas 31.7% of participants had in person contact with a peer navigator 6 times or more. Similar distributions were found when asked about telephone contact with a peer navigator in the past 6 months. Most participants (69.5%) reported telephone contact with their peer navigators between 1 to 5 times, while less than a third of participants (30.5%) reported telephone contact with their peer navigators on 6 occasions or more.

Most FSWs who had contact with a peer navigator were reminded of their HIV care appointments by their peer navigators (65.9%). Furthermore, over half of the women reporting having contact with a peer navigator also reported being accompanied by their peer navigators to a clinic appointment in the past 6 months (52.9%). For example, 44.8% of FSWs reported having

their peer navigators accompanied them to an HIV counseling and treatment appointment, while 10.3% reported their peer navigators accompanied them to a sexually transmitted infections (STI) counseling appointment. Women also reported being accompanied by their peer navigators to other services or activities related to their HIV treatment and care including to collect medications or test results (data not shown in table). In addition, peer navigators also provided support outside of HIV care services. In fact, 13.8% of FSWs reported their peer navigators accompanied them to gynecological appointments to obtain a Pap smear test, while other women also reported accompaniment by their peer navigators to violence counseling, family planning counseling, and talks or workshops for FSWs (data not shown in table). Overall, over a quarter of FSWs engaging with peer navigators reported receiving accompaniment by their peer navigators to appointments not related to their health in the past six months (25.6%).

**Table 7-1.** Peer Navigation activities among FSWs living with HIV

| | n | % |
|---|---|---|
| Any contact with peer navigator about HIV related services and care in the past 6 months | | |
| No | 124 | 58.8 |
| Yes | 87 | 41.2 |
| In person contact with a peer navigator in the past 6 months* | | |
| Between 1-5 times | 56 | 68.3 |
| 6 times or more | 26 | 31.7 |
| Phone contact with a peer navigator in the past 6 months* | | |
| Between 1-5 times | 57 | 69.5 |
| 6 times or more | 25 | 30.5 |
| Has been reminded of clinic appointments by your peer navigator in the past 6 months* | 54 | 65.9 |
| Has been accompanied by your peer navigator to clinic appointments in the past 6 months | 46 | 52.9 |

| | | |
|---|---|---|
| Type of accompaniment provided by peer navigator: | | |
| HIV counseling and treatment | 39 | 44.8 |
| STI counseling | 9 | 10.3 |
| Has been accompanied by peer navigator to appointments not related to health in the past 6 months* | 21 | 25.6 |

*n=82

*The Role of Peer Navigation in Linkage and Retention in HIV Care*

Consistent with the quantitative results, less than half of the participants in the qualitative subsample spontaneously recalled experiences with peer navigation and support as they recounted their experiences with HIV treatment and care services. However, among the women who mentioned experiences with peer navigation and support, it was clear the pivotal role that peer navigation had in their experiences and the quality of their HIV care services, specifically, the pivotal role that peer navigation and support had in ensuring that they were able to link to HIV care after confirmed HIV positive diagnosis. One participant recalled her experience linking to HIV care after finding out her diagnosis and feeling unwell:

> *"I found out [about my doctor] from [my peer navigator], [my peer navigator] gave me the talk… around the time I met [her], she lives with HIV, she tells me that she is going to take me to an [HIV] center to get me my medications, she went through everything with me, [my peer navigator], since they gave me my medications."* [32 years old, 7 years living with HIV]

When describing her experience engaging with HIV care, another participant recalled how she is at her current HIV clinic because she was brought to the location by her peer navigator. This

participant described *"just suffering"* for almost two years after her diagnosis, because she did not know how to get the HIV care that she needed. This participant reported finally engaging in HIV care through the help of a female friend who is also living with HIV and her peer navigator. She recalled *"I have a friend, but she doesn't live there...That was the one who brought me here to the hospital, to the doctor, the one who brought me [to the doctor], that was [my peer navigator]."* The same participant explained how she has now become active in providing support, navigation and accompaniment to other women who are diagnosed with HIV just like the type of navigation and support that she received from her peer navigator despite knowing the risk of discrimination and stigma that she may face by members of her community. She explained:

> *"That is why in [my community], they have said that I have HIV, because since I know that [in my community], one [person] has it, I go and look for [that person] and tell them 'I know where to take you, come let's go,' like the woman I took [to this clinic], I went and took [the person] to [my peer navigator], and [then] I took another woman to [my peer navigator] and I went with her to the doctor, so [the community] say 'that one has HIV', because when you have HIV, you go [to that clinic]."* [41 years old, 12 years living with HIV]

One participant also recalled her first engagement with HIV care services. She was able to access a HIV comprehensive care facility through her neighbor, who was also working as a peer counselor for FSWs and is a known activist among this community. When speaking about her experience, she recalled:

> *"Because of her I am alive…When I got sick, then, she told me, 'come here,' I told her 'come, I'm going to tell you [about my HIV diagnosis] that I know that you are going to help me,'…then she told me 'don't despair, don't worry I'm going to help you' and she took me to the [the HIV clinic] with [my] doctor…[I trusted her] because I don't know, she proved to be trustworthy, she proved to be very trustworthy."* [49 years old, 7 years living with HIV]

Another participant also shared her own experience providing peer navigation services to other women living with HIV. This participant would recall stories when she provided support and attempted to link other women to the HIV treatment and care they needed while reflecting on her own experience engaging with care. As seen in this next excerpt, this participant described the struggle she experienced in trying to get a participant engaged in her HIV care and adherent to her HIV medication:

> *"We get her a Megestrol (drug to treat loss of appetite), a Megestrol, a syrup and we send her other medications, and the stepmother since she arrived gave her a cap of Megestrol so that she would get an appetite for her to eat, but it is not worth having an appetite if she does not take the [ART] medications."* [39 years old, 19 years living with HIV]

The same participant also reflected on her success at being able to link and most importantly retain people living with HIV to care. She explained:

> *"Since we, [peer navigators and counselors], have entered [the clinic] there, those areas [calling patients with high viral load back] have improved a lot, the patient is being made to return to the [clinic], we visit them, call them and verify everything, but before*

*no, before the patients they were lost, many, we have retained many patients, a lot, and patients from years ago [came back]."* [39 years old, 19 years living with HIV]

*Promoting Agency through Peer Navigation*

Among participants who discussed experiences with peer navigation and support, there was a sense of agency or self-awareness of their own ability to make decisions about their own HIV treatment and care. This level of self-awareness was aided by the information and support that peer navigators often provided to participants. One participant, who also serves as a peer navigator, promoted FSWs' own level of awareness and control about their HIV treatment by discussing strategies for treatment adherence with them. She explained how she speaks to other FSWs living with HIV and shares her strategies for how they could also be adherent to their ART given their occupation. As she was explaining her strategies, she recalled letting other FSWs living with HIV know that *"you make a change, you are going to make a change, you sleep during the day"* and alerts them to reconsider when and how they take their medications given their own schedules. The same participant also described how she handles her own disagreements with clinic staff. It is evident from this participant's experience with HIV care services that she utilizes her own voice and activism to promote better quality of care services, while also encouraging other individuals living with HIV to better advocate for themselves. She recalled:

*"That day exploded, [participant recalling the day she initiated a protest because providers were not going to care for patients] they told me 'shut up' and [I said] 'I'm not going to shut up.' […] then the administration [from the clinic] said 'what is happening here?' [I said] we are protesting because here are all the patients from the morning and*

*the ones from the afternoon just arrived and already the doctors…left and that is not possible."* [53 years old, 38 years living with HIV]

Peer navigation and support was not limited to only sharing information with participants about HIV treatment and care services, but also served as a linkage for women to connect to other groups that could provide additional support to FSWs, in particular. One participant recalled her sentiments related to knowing that she will need to be on an ART regimen for the rest of her life, and how through peer activities and support, introduced by her peer navigator, she surpassed any concerns that this may have imparted:

*"I was already prepared [to begin my ART medication], I no longer had any feelings [about having to take ART for the rest of my life], and to me that was normal, as I was already here [speaking of the Abriendo Puertas support group] and I had come here to listen to the talks every so often… I already knew about all of that [medication regimen and adherence]."* [41 years old, 12 years living with HIV]

In another example, one participant reflected on her own experience navigating the HIV care environment with the support of her peers, and it is that experience which has propelled her to desire a job wherein she serves to provide navigation and support to assist other women living with HIV. In the following, this participant explained her rationale:

*"[I would like to work and help more women who live with HIV] Yes, I would like to help people who don't have that…that support that I have had, that is, you always need that support, especially when you are recently diagnosed, but you always need that support, that is to always know that there is a person who thinks of you...that you have that [gives you a] helping hand, that even if you feel that you are falling there is a person who can*

*lift you, even psychologically I would always like I mean, I want to,…, I want to help people who live with my condition and who may not have that person who can help them…there is a moment when you feel that [you are] alone, that you feel overwhelmed, that you feel sad, that you feel … that you need at least one person to tell them about your problems…and even if you have a lot of family, even if you have many friends, it is not the same for you to sit with a person who is living the same [experience] as you or who has lived the same [experience] as you, who is going to understand the same, who is going to feel the same, who is going to know what you are saying."* [34 years old, 14 years living with HIV]

*Promoting Access to More Comprehensive Services*

Through peer navigation and support, some participants were also able to better engage with HIV care services, such that, women were able to have more information on which clinics or facilities to seek as they provide more holistic or comprehensive care. One participant recalled her experience trying to transfer to a clinic with help from her peer navigator:

*"[My peer navigator] wanted to take me to a [HIV care clinic] here in the capital…because in this [new clinic] they gave me my groceries, they do my analysis, I don't have to go out around the whole country, they do everything on one site."* [32 years old, 7 years living with HIV]

Furthermore, when reflecting about her HIV care experience, another participant expressed that through her involvement in providing peer support as part of an organization for FSWs, she has been able to link women to more comprehensive care, which extends beyond HIV care. This participant expressed the following:

> *"Look, for example here [at this site] they come and [they] do a study on you, if you come out with a disease, an infection, they also give you the medicine, which is a help because you do not have to buy it, it is a help. And there is much more. You can learn many things that can allow you to live by just coming here, the workshops they give here are things that allow you to survive economically because [you could learn] a craft…with that I can survive…"* [41 years old, 7 years living with HIV]

*The Role of Peer Navigation in the HIV Quality of Care*

Consistent with the qualitative findings, quantitative results further supported the contributing role that peer navigation has in the quality of HIV care. When exploring the associations between relational aspects of quality of care and overall satisfaction of HIV care by engagement with peer navigation (**Table 7-2**), we found two significant associations. First, the vast majority of participants that reported engaging with peer navigation reported more respectful treatment by clinic staff. Specifically, 97.5% of FSWs who engaged with peer navigators reported always being treated with respect during care appointments, compared to 86.8% of FSWs who reported not engaging in peer navigation (p-value of 0.009). In addition, we found a significant association between satisfaction with HIV care services and peer navigation. Almost three-quarters of participants who had engagement with a peer navigator rated HIV care services as very good or excellent (72.8%) compared to just over half of participants who had no engagement with a peer navigator (52.1%; p-value of 0.003). Our results revealed no significant associations between peer navigation services and patient-provider communication.

**Table 7-2.** Relational factors of quality of care

| | No Peer Navigation (n=121) | | Peer Navigation (n=81) | | p-value |
|---|---|---|---|---|---|
| | n | % | n | % | |
| The staff at the clinic where you get your HIV care always treats you with respect | 105 | 86.8 | 79 | 97.5 | 0.009 |
| Patient-Provider Communication (PRA Score) (median, IQR) | 45 | (43, 45) | 45 | (44, 45) | 0.127 |
| Overall, the services at the clinic where you get your HIV care are very good or excellent | 63 | 52.1 | 59 | 72.8 | 0.003 |

We further explored the associations between engagement with peer navigation and always being treated with respect in the HIV clinic environment and the rating of HIV care services through random-effects multivariable logistic regressions. Our results indicate that after controlling for sociodemographic characteristics and years living with HIV, the relationship between the two outcomes of interest and peer navigation remained significant. As shown in **Table 7-3**, FSWs who reported engaging with a peer navigator have 6.65 times greater odds of also reporting always being treated with respect (95% CI: 2.32 – 19.02) in their HIV care environments compared to those with no engagement with peer navigation. In addition, compared to FSWs with no engagement with peer navigation, FSWs who reported engaging with a peer navigator had 2.57 times greater odds to rate the overall quality of HIV services received as very good or excellent (95% CI: 1.77 - 3.74).

**Table 7-3.** Associations between quality of care measures and peer navigation (n=201)

| | Always being treated with respect at HIV care facility | | Very good or excellent services at HIV care clinic | |
|---|---|---|---|---|
| | AOR | 95% CI | AOR | 95% CI |
| Age | 1.04 | 0.96 - 1.13 | 1.02 | 0.98 - 1.06 |
| Relationship: With a partner | 0.93 | 0.56 - 1.55 | 1.68 | 0.86 - 3.31 |
| Primary school or less | 0.71 | 0.18 - 2.87 | 1.47 | 0.99 - 2.17 |
| Years living with HIV | 0.98 | 0.89 - 1.09 | 1.01 | 0.96 - 1.05 |
| Any peer navigation | 6.65** | 2.32 - 19.02 | 2.57** | 1.77 - 3.74 |

CI based on robust standard errors
** $p<0.01$

The association between high levels of satisfaction with HIV care services and peer navigation was further confirmed through the qualitative findings. Specifically, when asked about recommendations that could improve the HIV care experience of FSWs, one recommendation was for clinics to establish navigation services for FSWs living with HIV. As explained by the following participant, navigation services could help women better understand and advocate for their own care:

> *"The guidance, that there is always a person with you there, constantly, telling you and reading, inquiring because if you do not start inquiring and asking, [or have] the curiosity to ask, [then] you know that you will live all the time locked up and you will not learn anything."* [37 years old, 12 years living with HIV]

**Discussion**

The results of our study confirm the pivotal role that peer navigation and support have in improving the quality of HIV treatment and care services by addressing the structural and social barriers that hinder the experience of FSWs as they navigate through the HIV care environment.

Our study revealed the significant role of peer navigators in ensuring more respectful treatment by clinic staff, with FSWs who engage in peer navigation having greater odds of being treated with respect by clinic staff. This finding supports calls by UNAIDS to create more integrated services that dismantle discriminatory practices within the healthcare environments for PLHIV, including FSWs.[26] It is clear that having the support from peer navigators acts as a protective factor against experiencing poor treatment in healthcare facilities, which in part could be due to the accompaniment that peer navigators provide to their peers. This is important as disrespectful

and abusive treatment by clinical care providers has been linked to missed HIV care appointments and disengagement in care.[13] Furthermore, our quantitative and qualitative findings support those by Alvis-Estrada and colleagues[7]: that peer navigators are providing support to FSWs in other areas outside of HIV care. For example, in our study, peer navigators provided accompaniment to family planning, violence counseling, and gynecological appointments, while they also linked FSWs to more comprehensive care with services that exceeded HIV care. This highlights the more comprehensive role that peer navigation play in the health and well-being of PLHIV.

As we stipulated using Freire's theory of critical consciousness,[27,28] providing the space for culturally and linguistically appropriate exchanges allows individuals to address structural barriers that perpetuate inequality. Through peer navigation and support we argued that FSWs will be able to begin addressing the structural and social barriers that hinder their ability to receive quality HIV treatment and care. Our findings support this conceptualization of the role of peer navigation and support. In our study, having a positive HIV diagnosis was not sufficient to encourage FSWs to link to HIV care as confusion about how to course through healthcare structures, along with the deep-rooted fear and stigma that comes with a positive HIV diagnosis, serve to divert FSWs from assessing HIV treatment and care services. As a result, FSWs relied in the assistance of peer navigators to link to care and begin to understand the dynamics shaping the clinic environment. Furthermore, peer navigation and support provided a mechanism for woman to establish their own control over their treatment and care, thus promoting greater agency among this often-stigmatized group. Peer navigation and support serve as an avenue for women to learn about best practices, where to find more comprehensive care services, and strategies for

improving ART adherence and reaching viral suppression. Ultimately, FSWs were able to better navigate through the complex HIV care environments through established support generated by their peers. These findings corroborate the gains correlated with the utilization of peer navigation among PLHIV.[1,2,6]

In addition to the UNAIDS call for the use of navigation services as a strategy for reaching the 95-95-95 HIV epidemic goals by 2030,[7,14] FSWs themselves find the use of peer navigation as a promising strategy for improving their own experiences with HIV treatment and care services. Furthermore, data from this study also supports that FSWs who engage with peer navigators report better overall satisfaction with HIV care services. These findings are promising given that investments in peer navigation have been found to be cost-effective in addressing behavior among people with chronic illnesses,[31] and given the support by FSWs themselves, this could be an approach that enhances the existing HIV care services to ensure the success of positive HIV outcomes among this population.

This study is not without limitations. Qualitatively exploring peer navigation and support was an emergent topic that stemmed from the exploration and analysis of the experiences of FSWs engaging in HIV care. As such, more in-depth exploration of the role of peer navigation and support and the healthcare environment's views and perception about peer navigation was not explored for this study. However, we believe that its spontaneous emergence through the analytical process serves only to magnify the poignant role that peer navigation and support have in assisting FSWs to navigate through HIV care services and reach optimal HIV outcomes of ART adherence and viral suppression.

Peer navigation is a strategic approach that not only FSWs have proposed as a recommendation to strengthen the quality of their HIV care, but has also been found to be associated with better satisfaction with overall HIV care services. Among FSWs living with HIV, peer navigation is instrumental in addressing barriers to linkage and retention in care, promoting more comprehensive care, and enhancing more respectful HIV care environments. Integration of peer navigation into formal HIV care environments should be considered as a strategic approach to improving the quality of HIV care services and subsequently attaining positive HIV outcomes among FSWs.

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## Chapter 8: Integrated Discussion and Conclusion

The overall objective of this dissertation was to explore the relationship between the quality of HIV care, peer navigation and HIV behavioral and biological outcomes among female sex workers (FSWs) living in the Dominican Republic (DR). This objective was accomplished through the use of quantitative and qualitative methodologies aiming to (1) explore the healthcare dynamics contributing to the quality of HIV care experienced by FSWs; (2) examine the relationship between the quality of HIV care and HIV outcomes (antiretroviral therapy [ART] adherence and viral suppression) among FSWs; and (3) describe the contributing role of peer navigation and support on the quality of HIV care experienced by FSWs.

Manuscript 1 (Chapter 5) utilized a mixed methods approach to provide a more nuanced description of the healthcare experiences and clinic's characteristics, resources and operations that contribute to the quality of HIV care received by FSWs. Findings from this study acknowledged the impact that structural and relational aspects of care have in influencing the quality of HIV care, and which could subsequently impact successful achievement of positive HIV outcomes among FSWs. Our findings support the growing evidence surrounding the impact that the clinic environment and patient-provider dynamics have in shaping the experiences of FSWs as they navigate the HIV care continuum, and could lead to disengagement in HIV care and sub-optimal HIV outcomes.[1-7] In particular, findings in this study highlight the impediments to achieving quality HIV care brought on by insufficient clinic resources to provide ART to patients, the associated HIV care costs, and limited comprehensive care services, all of which contribute to the dissatisfaction in the HIV care experience of FSWs. Furthermore, our findings

underscore the pivotal role that the patient-provider dynamic has in promoting quality HIV care. Poor treatment by providers -such as being treated carelessly, without respect or dignity- was noted as a barrier to accessing quality HIV care and often leads to the disruption of FSWs' current HIV care services. Effective communication by providers was also seen as a driver for quality of HIV care, as women reported an appreciation for healthcare providers that share clear and complete information as it relates to their HIV treatment and care options. Lastly, results from this study also uncovered the opportunity of strengthening the quality of HIV care through the engagement of FSWs in advocating and controlling their own HIV treatment and care plans. Our results suggest that FSWs were able to exert their own agency- via their own immersion in understanding their treatment and the biological implications of their treatment- to better advocate and demand for quality HIV care services. This was not only done through treatment literacy, but was also observed when FSWs lack trust in healthcare providers, which led to a desire of gaining more control over treatment in order to maintain good health.

Manuscript 2 (Chapter 6) expanded on the findings from Manuscript 1 by quantitatively assessing the relationships between quality of HIV care, treatment literacy and HIV outcomes - specifically, ART adherence and viral suppression. In this manuscript, we conceptualized the rationale for model development utilizing the Donabedian Framework for quality assurance[8,9] and Gidden's Structuration Theory[10] to understand the potential relationship between quality of care and agency -captured through treatment literacy -on ART adherence and viral suppression. This conceptualization was motivated by the findings from Manuscript 1 on the most salient structural and relational aspects of care influencing FSWs' experience with HIV treatment and care services, and under the assumption that these structural and relational aspects of care, along

with treatment literacy, could impact FSWs' success towards viral suppression. Findings from this study suggest greater treatment literacy was associated with an increased odds of reporting ART adherence and viral suppression. These findings exacerbate the need to support efforts to improve treatment literacy, with a particular focus on engaging with patients to encourage a clear understanding of the effect of HIV treatment on viral load and CD4 count. In addition, patient-provider and patient-clinic dynamics revealed to have a direct effect in promoting viral suppression, highlighting the importance of interpersonal interactions between FSWs and clinical care providers. In particular, participants in our study who reported better patient-provider communication and reported always being treated with respect at the clinic where they receive their HIV care had greater odds of being virally suppressed. Lastly, addressing the out-of-pocket associated costs of HIV care by both acknowledging their impediment to achieving optimal HIV outcomes and providing pathways to remediate the negative effect that these costs of care have on HIV outcomes is imperative as we continue to strive to provide more equitable care to FSWs living with HIV. In our study, increased cost of HIV care was negatively associated with reporting ART adherence and being virally suppressed.

Manuscript 3 (Chapter 7) focused on describing the role of peer navigation and support on enhancing the quality of HIV treatment and care services experienced by FSWs. Drawing from the results of Manuscripts 1 and 2, we harnessed the pivotal role that quality of HIV care has in the experiences and satisfaction among FSWs, as well as on the success of FSWs' pathway to viral suppression. As such, this paper sought out to uncover the potential influential role of peer navigation and support in enhancing the quality of HIV care received by FSWs through a mixed methods approach, combining quantitative and qualitative analyses. In this study, we

conceptualized the role of peer navigators through Freire's theory of critical consciousness,[11,12] which posits that providing the space for culturally and linguistically appropriate exchanges allows individuals to address structural barriers that perpetuate inequality. As such, we argued that FSWs would be able to address the structural and social barriers that hinder their ability to receive quality HIV treatment and care through peer navigation and support. This conceptualization was proven to be correct as our results indicate that FSWs relied on the assistance of peer navigators to link to care, even after positive HIV diagnosis, and begin to understand the dynamics shaping the clinic environment. Furthermore, our study revealed the significant role of peer navigators in ensuring more respectful treatment by clinic staff, with FSWs who engage in peer navigation having greater odds of being treated with respect. Lastly, our study found that FSWs themselves find the use of peer navigation as a promising strategy for improving their own experiences with HIV treatment and care services. Moreover, data from this study also revealed that FSWs who engage with peer navigators report better overall satisfaction with HIV care services. Ultimately, our study found that peer navigation and support is a strategic approach that has been proposed by FSWs to strengthen the quality of their HIV care, aids in promoting agency among FSWs, and is also associated with better satisfaction with overall HIV care services.

### *Implications for Programs and Research*

This dissertation has important implications for future programmatic efforts aiming to improve HIV outcomes among FSWs through investments in quality of care. Understanding the experiences and the role that quality of HIV care play in establishing positive HIV outcomes

supports the re-allocation of program resources towards a variety of structural and relational factors found to be associated with FSWs' successful engagement in care and subsequent path towards viral suppression. Key areas for future programmatic efforts include: (1) investing in sensitivity training for clinical care providers, (2) securing the allocation of clinic resources, (3) addressing the financial burden associated with cost of HIV care, (4) promoting HIV treatment literacy, and (5) formalizing and expanding peer navigation and support services across healthcare settings.

*Investing in Sensitivity Training*

Studies have found that discrimination or being treated with contempt or disrespect by clinical care providers could hinder engagement and retention in care.[6,7] Our findings confirm this notion and further expanded the effect of respectful treatment and positive patient-provider communication on achieving viral suppression among FSWs living with HIV. As such, our findings support the delivery of care with dignity as it forms a central aspect of how individuals assess the quality of treatment and care services they receive, and given its association with achieving positive HIV outcomes. These findings emphasize the need for sensitivity trainings for healthcare providers and clinic staff to promote techniques to aid in conveying medical information respectfully, effectively, and with an understanding of the needs for people living with HIV (PLHIV) and in particular those engaging in sex work. This has been an important area of work that has been stressed by other studies,[13-15] and research supports the benefits of this approach in increasing effective communication while decreasing judgmental and demeaning attitudes towards key populations like sex workers.[16] Lastly, sensitivity trainings align with calls

by UNAIDS to promote respectful care and end discriminatory practices within the healthcare environments for PLHIV, including FSWs.[17]

*Securing the Allocation of Clinic Resources*

Clinic assessments and qualitative data revealed the substantial issues surrounding insufficient ART stock. In our study, insufficient ART stock was associated with dissatisfaction in the quality of HIV care as it led to unwanted changes in ART regimen, increased number of visits to clinics to collect ART due to changes in distribution patterns, and overall uncertainty about continuity of HIV treatment. Our findings underscore how imperative it is for the clinics to address the ART stock shortage as this medication shortage impacted FSWs' ability to control their own treatment adherence as observed in other contexts.[5] Efforts should be made to ensure a consistent distribution schedule of ART to patients to maintain willingness to adhere to treatment regimens and reduce feelings of vulnerability or uncertainty as a result of ART shortages in clinics.

*Addressing the Financial Burden Associated with Cost of HIV care*

Results from both qualitative and quantitative data stress the financial burden that the costs associated with HIV care creates for FSWs. Qualitative data found that the financial impact of associated HIV care costs creates a heavy burden as FSWs engage in care and was attributed to dissatisfaction with HIV care, which could subsequently contribute to disengagement with HIV treatment and care services. Furthermore, quantitative findings found an association between high HIV associated costs and decrease odds of ART adherence and viral suppression among FSWs. These results underscore the need for programming to address the barriers associated with

the financial constraints resulting from HIV care given its impact on the quality of HIV care and successful HIV care continuum outcomes among FSWs. Financial incentive programs, such as voucher programs, wherein patients are given financial incentives for transportation and food, should be explored as a type of strategy to address the financial vulnerability that is experienced by FSWs when accessing HIV care. This strategy has been found effective in other settings among PLHIV, where incentives for food support were associated with ART initiation,[18] while financial incentives, in the form of quarterly gift cards, were associated with viral suppression.[19]

*Promoting HIV treatment literacy*

Our findings recognize the positive contributions of treatment literacy on FSWs' increased engagement with their own HIV treatment and care. Furthermore, quantitative results also revealed the associations between treatment literacy and reporting greater odds of ART adherence and being virally suppressed. Our findings support the calls for the promotion of treatment literacy for PLHIV, including key populations like FSWs. Promoting treatment literacy could be one of the first steps in getting patients involved in their care as understanding these concepts could aid in achieving optimal HIV outcomes, while also enhancing patients' own sense of power (their agency) and their contributing role in treating their disease and achieving an undetectable viral load. This supports evidence suggesting that health literacy is a critical component in empowering patients to advocate and accomplish successful health outcomes,[20] and contributes to evidence supporting the associations between treatment education and positive HIV outcomes.[21,22]

*Formalizing and Expanding Peer Navigation and Support Services*

Our study revealed the pivotal role of peer navigation and support in assisting FSWs' link to HIV care after diagnosis, obtaining more comprehensive care services, and promoting agency by improving FSWs' skills to more strategically and effectively engage with the clinic environment and health care providers. In addition, peer navigation was associated with greater odds of being treated with respect in the clinic environment, and greater overall satisfaction with HIV care services. These results recognize the influential role of peer navigation and support in improving the quality of HIV care among FSWs, and more strategic efforts should be placed in investing in formalizing and expanding peer navigation and support services as part of the standard of HIV care. Given the increased benefits of peer navigation and support, it is not surprising that the UNAIDS has made a call for the use of navigation services as a strategy for reaching the 95-95-95 HIV epidemic goals by 2030.[23,24] Furthermore, our study suggests that FSWs themselves find the use of peer navigation as a promising strategy for improving their own experiences with HIV treatment and care services. These findings are promising given that investments in peer navigation have been found to be cost-effective in addressing behavior among people with chronic illnesses,[25] and given the support by FSWs themselves, this could be an approach that enhances the existing HIV care services to ensure the successful achievement of positive HIV outcomes among this population.

Notwithstanding the important programmatic implications from this dissertation, one area that requires further research to close the knowledge gap on the associations between quality of care, peer navigation and HIV outcomes among FSWs is exploring the integration of peer navigation into HIV care services and the perceived role of peer navigators in HIV healthcare settings. Our results indicated that peer navigators provide accompaniment, support and advocacy to FSWs

beyond HIV care services. Future research exploring the perceptions of peer navigators on their contribution to quality HIV care and positive HIV outcomes, along with the perceptions of healthcare providers of the contributions of peer navigators to the quality of HIV care will serve to provide a more nuanced description of the support peer navigators receive from healthcare environments, and address the potential challenges encounter by peer navigators when providing services to FSWs living with HIV. Furthermore, future research should aim at understanding the experiences of healthcare providers rendering care to FSWs living with HIV. Our clinic assessment revealed the potential oversaturation of patients in some of the HIV comprehensive care facilities, and structural barriers (such as ART stock shortage) were found to highly influenced the quality HIV care experience of FSWs. Nevertheless, understanding the experiences of healthcare providers navigating the structural challenges may increase our understanding of feasibility of HIV programming efforts to address impediments to quality HIV care at the structural level.

### *Strength and Limitations*

This dissertation is not without limitations. First, it is important to acknowledge that our sampling strategy has its biases. FSWs in our study had to have disclosed at least to one person their HIV status (e.g., the study recruiter, peer navigator), and as such, this is a sample of FSWs that are likely to be more aware of their HIV status and in turn potentially more engaged in care. Nevertheless, research conducted by the parent study team continues to highlight that despite high linkages to care among this population, FSWs living with HIV in the DR continue to experience sub-optimal HIV outcomes such as sub-optimal levels of viral suppression.[26,27] This

emphasized the need for the current research as it provided further insight into the potential causes that may be leading to sub-optimal HIV outcomes among this population. In addition, the study relies on data collected at the second round of the parent study. This presents a study limitation given that the cross-sectional nature of the study limits the ability to draw causal inferences about the relationships between quality of HIV, and ART adherence and viral suppression. Lastly, qualitatively exploring peer navigation and support was an emergent topic that stemmed from the exploration and analysis of the experiences of FSWs engaging in HIV care. As such, more in-depth exploration of the role of peer navigation and support and the healthcare environment's views and perception about peer navigation was not explored for this study. However, we believe that its spontaneous emergence through the analytical process serves only to magnify the poignant role that peer navigation and support have in assisting FSWs to navigate through HIV care services and reach optimal HIV outcomes.

Despite these limitations, there are also several important strengths to the study. A particular strength is that the data used to address the research questions draws from self-reported social and behavioral data of FSWs, as well as biological assessments (i.e., viral load), clinic level observations, and semi-structured in-depth interviews with FSWs. Being able to able to draw from these sources of information serves to strengthen the quality of our analysis and ability to address the overall research question and subsequent aims. Furthermore, using this mixed methods approach allowed for further assessment of findings and themes. For example, the Student Investigator was able to expand on qualitative findings using quantitative data to assist in building the conceptualization for model selection to explore the objective of Manuscript 2. In addition, another strength of the dissertation has been the direct involvement of the Student

Investigator in the development of instruments, both quantitative and qualitative, which have allowed her to have full immersion on the measures and variables to be tested and observed the validity of these measures in other research analyses. Furthermore, the Student Investigator had the opportunity to travel to Santo Domingo, DR to collaborate with IDCP researchers, peer navigators, and FSWs, which has served to further enhanced the understanding of the Student Investigator on the socio-structural context of the study population. Lastly, given the Student Investigator's native Spanish language skills, data has been analyzed in Spanish and questions have been directly addressed and resolved with the local research team, thus serving to increase the fidelity of the results.

***General conclusions***

This dissertation highlights the importance of quality of HIV care and treatment literacy in the experiences of FSWs as they navigate HIV treatment and care services, and in achieving optimal HIV outcomes. Program and investment efforts should be made to promote FSWs' understanding of their HIV treatment, further train providers to deliver HIV care to FSWs with dignity and respect, and address the financial burden experienced by FSWs due to HIV care and the impact that this has on achieving ART adherence and viral suppression. Peer navigation is a strategic approach found to be associated with better satisfaction with overall HIV care services. Among FSWs living with HIV, peer navigation and support is instrumental in addressing barriers to linkage and retention in care, promoting more comprehensive care, and enhancing more respectful HIV care environments. Integration of peer navigation into formal HIV care environments should be considered as a strategic approach to improve the challenges observed in

the relational and structural aspects of HIV care found to be hindering the experiences of FSWs as they navigate the HIV care environment.

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**The George Washington University**
**Milken Institute School of Public Health** Washington, DC
**Data Analyst** July 2020 – Present

- Support quantitative and qualitative data analysis for NIMH-funded longitudinal study aiming to improve the health vulnerable women and reduce the ongoing transmission of HIV in Tanzania and the Dominican Republic (R01MH110158).
- Assist in the development of research project academic manuscripts and other dissemination materials.

**American University**
**Center for Health, Risk and Society** Washington, DC
Research Program Coordinator Dec. 2018 – June 2020

- Collaborated in the development of new NIH and University-wide research grants.
- Assisted in the management of Center budget, including the management of the Center for Health, Risk and Society Research Fellows and Research Assistants.
- Organized research workshops for Center for Health, Risk and Society Research Fellows and Research Assistants.

- Collaborated in the development of quantitative research instruments for a healthcare provider survey as part of a Phase III clinical trial for the efficacy, acceptability, tolerability and satisfaction of a long-acting injectable antiretroviral therapy, with cabotegravir and rilpivirine.
- Collaborated in the development of quantitative and qualitative instruments, data collection, data analysis and dissemination of R01 NIH Research grant exploring the role of social determinants, including stigma and social cohesion, along the pathway to viral suppression among female sex workers living with HIV in the Dominican Republic and Tanzania (Grant #: R01MH110158; PI: Dr. Deanna Kerrigan).

**Johns Hopkins Bloomberg School of Public Health**
**Department of Health, Behavior and Society** Baltimore, MD
Graduate Research Assistant Aug. 2016 – Dec. 2018

- Collaborated in the qualitative and quantitative data analysis of a project aiming to identify the role of social determinants, including stigma and social cohesion, along the pathway to viral suppression among female sex workers living with HIV in the Dominican Republic and Tanzania (Grant #: R01MH110158; PI: Dr. Deanna Kerrigan).
- Collaborated in the qualitative collection and analysis of a Phase III clinical trial for the efficacy, acceptability, tolerability and satisfaction of a long-acting injectable antiretroviral therapy, with cabotegravir and rilpivirine.

**The World Bank**
**Transport & ICT – GP** Washington, DC
Short Term Consultant Sept. 2014 – Jan. 2017

- Collaborated in the development of a study aiming to explore and measure sexual harassment in public transportation in Mexico City, Mexico.
- Conducted oral presentations, in English and Spanish, on the evaluation design, implementation, and findings to the World Bank team and other key stakeholders.
- Assisted with the development of evaluation data collection instruments in English and Spanish.
- Prepared Institutional Review Board (IRB) materials and assist in the oversight of data security and confidentiality procedures.
- Trained and managed data collection teams.
- Performed quantitative data analyses to support the development of final reports and academic manuscripts.

**The Susan Thompson Buffett Foundation**
**Research and Evaluation Unit** Omaha, NE
Research Consultant June 2015 – Aug. 2016

- Collaborated in the development of *Request for Proposals* (RFPs) of research projects related to women's health and higher education scholarships.
- Developed systematic reviews of literature to help inform evaluation objectives of future projects.
- Performed quantitative data analyses to explore the determinants of scholarship eligibility and awardee status.

**Ibis Reproductive Health** Oakland, CA
Research Consultant June 2015 – July 2016

- Collaborated in the writing of a research report for funders and the development of a peer review manuscript exploring abortion stigma in the Dominican Republic.
- Conducted qualitative data analysis of in-depth interviews.

**The George Washington University**
**Milken Institute School of Public Health**
***Avance* Center for the Advancement of Immigrant/Refugee Health** Washington, DC
Research Associate July 2014 – June 2015

- Collaborated with community partners in the planning, implementation and documentation of the *Adelante* intervention, a community-based, multi-level intervention to address the co-occurrence of substance abuse, violence and sexual risk among Latino youth residing in Langley Park, MD.
- Provided research support and collaborate in the development of the study design, instruments, and IRB protocols.
- Assisted with quantitative and qualitative data collections.
- Collaborated in the planning of training activities, including university lectures, coordination of conference activities, development of online training modules, and community trainings.
- Contributed to the development of community engagement and communications activities in both English and Spanish, including assisting with messaging activities/campaigns, developing dissemination materials, and creating online engagement tools.
- Assisted with the preparation of grant applications.
- Contributed to compiling and synthesizing research results, including scientific papers and presentations.

**Population Council – Mexico Office** Mexico City, Mexico
Program Researcher Aug. 2012 – June 2014

- Provided research support and collaborated in the development, implementation, and monitoring and evaluation of research projects in Mexico and Central America in the areas of sexual and reproductive health (SRH), gender-based violence, indigenous health, migration, youth development, and other emergent topics related to SRH.
- Assisted with the development and application of research protocols, field training materials, and study instruments.
- Led the development of research instruments including national public opinion surveys, cognitive interview guides, and other quantitative and qualitative research tools.
- Performed quantitative and qualitative data analysis utilizing different software packages including SPSS, NVivo, Atlas.ti, and Deedose.
- Collaborated in the planning and implementation of data collection activities and field staff training for projects throughout the region.
- Contributed to compiling and synthesizing research results.
- Worked collaboratively to conceptualize and prepare proposals for funding, including those addressing new cross-cutting topics, and participated in other development-related activities including prospect research, new donor outreach, and donor stewardship.
- Maintained and strengthened positive relationships with stakeholders, including partner organizations, public sector collaborators, community organizations, donors, and other Council offices in the region and globally.

**Child Trends, Inc.** Washington, DC
Youth Development Research Analyst June 2011 – Aug. 2012

- Supported quantitative research tasks, including developing the content of surveys and other instruments, managing and manipulating data sets, executing quantitative statistical analyses by applying basic and advanced methods using SAS, and summarizing findings and results from surveys.
- Supported qualitative research tasks, including developing the content of qualitative research protocols for focus groups and in-depth interviews, analyzing and interpreting data using NVivo,

drawing conclusions from the data, and identifying the implications of the results and conclusions for policy and program practices.
- Supported the development of analysis plans and research instruments for impact evaluations.
- Conducted cognitive interviews to support the testing of performance measures.
- Conducted focus groups and in-depth interviews in support of implementation evaluation research tasks.
- Developed IRB materials and assisted in the oversight of data security and confidentiality procedures.
- Assisted in the review and synthesis of evaluation studies.
- Conducted literature reviews, including contributing original perspectives on patterns of findings.
- Collaborated in the reporting of research findings orally and in writing, and in the preparation of research grants.

**Population Council- Mexico Office** Mexico City, Mexico
Research Consultant Sept. 2009 – Aug. 2012

- Conducted research and performed data analysis on patient-led partner notification practices, Mexico City abortion legislation, and other reproductive health topics in developing countries to aid in the proper completion of research manuscripts.
- Translated monitoring and evaluation (M&E) instruments for current projects (Spanish-English).
- Conducted in-depth interviews to aid the M&E phase of a current project of rural and indigenous women residing in Oaxaca, Mexico.
- Performed qualitative data analysis of in-depth interviews and qualitative portions of surveys utilizing traditional manual analysis.
- Collaborated in the planning and execution of the Mexico City Ministry of Health sexual and reproductive health campaign for adolescents.
- Collaborated in the drafting of a concept paper for potential exploratory research to assess the problem of child marriage in four Latin American countries: El Salvador, Guatemala, Nicaragua and Mexico.
- Contributing author to professional manuscript.

**Academy for Educational Development (AED)**
**Center for Social Marketing and Behavior Change** Washington, DC
Senior Technical Associate- Research June 2010 – June 2011

- Collaborated in the development of work plans for Center projects, performed project assignments, and served as point of contact with clients.
- Collaborated in the writing of research reports, literature reviews, content analyses, and proposals.
- Supported qualitative research, including developing tools and instruments, collecting and analyzing data, and summarizing findings and results from focus groups, interviews, ethnographies, and usability tests.
- Supported quantitative research, including developing tools and instruments, collecting and analyzing data, and summarizing findings and results from surveys, content analyses, and monitoring and evaluation activities.
- Supported and executed analyses using quantitative software (SAS and SPSS), and qualitative software (NVivo).
- Supported primary research, such as environmental scans, reviews of academic literature in public health, social sciences, and behavioral sciences, searches of government surveys and epidemiological data (NHANES, BRFSS, etc.), and reviews of audience segmentation data, public opinion, and marketing surveys.

**The George Washington University**
**The Multicultural Student Services Center** Washington, DC
Program Coordinator Sept. 2008 – May 2010

- Assisted undergraduate students in the planning and implementation of student events for The George Washington University.
- Developed programs and activities to engage students in the University's Latino community.
- Led the development and management of the Latino Heritage Celebration programming for the George Washington University.

**Population Council- Mexico Office** Mexico City, Mexico
Summer Research Intern (MPH Practicum) May 2009 – Aug. 2009

- Contributed to the development of monitoring and evaluation (M&E) instruments for a young indigenous women empowerment project in Oaxaca, Mexico.
- Conducted field work (baseline in-depth interviews and qualitative/quantitative surveys) for an evaluation of indigenous women empowerment project as a part of the M&E phase and in support of Master's thesis titled "Exploring changing intergenerational social values surrounding sexuality among rural and indigenous Oaxacan women."
- Assisted in the peer-review of manuscripts submitted to *Studies in Family Planning*.

**Children's National Medical Center**
**Department of Diabetes and Endocrinology** Washington, DC
Clinical Research Assistant May 2007 – May 2009

- Supervised research patients participating in the University of South Florida's "Trialnet Natural History Study for the Development of Type 1 Diabetes."
- Performed data collection, registry, and shipment of specimens to research laboratories.
- Developed IRB certified patient consent and assent forms for the TrialNet study.
- Collaborated in the development of grant and research proposals for an approved youth diabetes program at Children's National Medical Center, "Small Steps to Success."

**Engineers without Borders**
**Potable Water and Hygiene Promotion Project** Washington, DC
Data Analyst July 2008 – Dec. 2008

- Performed data entry and data cleaning of surveys administered for a potable water and hygiene promotion project in Santa Clara, El Salvador using Microsoft Excel and SPSS.
- Analyzed SPSS outputs and presented data findings.
- Collaborated in the writing of the Santa Clara Water System Manual.

**Project Health, Inc.**
**STRIVE** Washington, DC
Program Coordinator Sept. 2007 – May 2008

- Provided mentoring and specialized support for adolescents (and parents) suffering from sickle cell disease.
- Oversaw and organized program training among volunteers.
- Maintained positive relations between hospital and STRIVE personnel via monthly meetings with social workers.
- Developed year-round curriculum, training manuals, and resource guides for program participants and their parents/guardians.
- Provided parental support for parents of adolescents suffering from sickle cell disease.

## TEACHING EXPERIENCE

**Johns Hopkins University**
**Krieger School of Arts and Sciences** Baltimore, MD
**Undergraduate Program in Public Health Studies** Sept. 2019 – Present
Gordis Teaching Fellow, Course – AS.280.451: Born a Girl: Issues in Women's Health from a Life Course Perspective

- Develop and teach a course focusing on key issues impacting women's health.
- Introduce theoretical perspectives for understanding women's health, specifically focusing on the life course perspective.
- Evaluate class assignments and provided students with adequate and complete feedback.
- Lead and engage students on class discussions.
- Provide mentoring for students.

**The George Washington University**
**Milken Institute School of Public Health** Washington, DC
**Department of Epidemiology and Biostatistics** Jan. 2016 – Present
Lecturer, Graduate course – PubH 6002: Biostatistical Applications for Public Health

- Introduce key topics in biostatistics and provide relevant examples from the field of public health.
- Evaluate class assignments and provide graduate students with adequate and complete feedback.
- Provide mentoring on biostatistical analyses to students.

**Johns Hopkins University**
**Bloomberg School of Public Health** Baltimore, MD
**Department of Health, Behavior and Society** Oct. 2018 – Dec. 2018
Graduate Teaching Assistant, Graduate course – 410.710.01: Concepts in Qualitative Research for Social and Behavioral Sciences

- Evaluated class assignments and provided graduate students with adequate and complete feedback.
- Assisted in leading class discussions on key concepts of qualitative research.
- Assisted on the development of course materials and class presentations.

**Johns Hopkins University** Baltimore, MD
**Bloomberg School of Public Health** Sept. 2018 – Oct. 2018
**Department of Health, Behavior and Society** Sept. 2017 – Oct. 2017
Graduate Teaching Assistant, Graduate course – 410.612.01: Sociological Perspectives in Health

- Evaluated class assignments and provided graduate students with adequate and complete feedback.
- Assisted on the development of course materials.

**The George Washington University**
**Milken Institute School of Public Health** Washington, DC
**Department of Epidemiology and Biostatistics** Jan. 2012 – May 2012
Limited Service Faculty, Graduate course – PubH 260: Advanced Data Analysis in Public Health

- Assisted in the development of class assignments to complement the course curriculum.
- Evaluated class assignments and provided graduate students with adequate and complete feedback.
- Provided technical assistance to graduate students when running programs and analyses using Statistical Analysis Software (SAS).

**The George Washington University**
**Milken Institute School of Public Health** Washington, DC
**Department of Prevention and Community Health** Jan. 2010 – May 2010
Graduate Teaching Assistant, Graduate course – PubH 370: Maternal and Child Health Foundations

- Developed group activities to complement maternal and child health curriculum.
- Evaluated group assignments and provided students with adequate and complete feedback.
- Developed group evaluation methodologies and materials for group assignments.

## AWARDS AND RECOGNITION

| | |
|---|---|
| 2020 | Dean's PhD Tuition Scholarship, Johns Hopkins Bloomberg School of Public Health |
| 2019 | Doctoral Distinguished Research Award, Johns Hopkins Bloomberg School of Public Health |
| 2019 | Center for Qualitative Studies in Health and Medicine's Dissertation Enhancement Award, Johns Hopkins Bloomberg School of Public Health |
| 2018-2019 | Gordis Teaching Fellow, Johns Hopkins University Public Health Program |
| 2017 | Doctoral Distinguished Research Award, Johns Hopkins Bloomberg School of Public Health |
| 2014 | Delta Omega Honorary Society in Public Health, Omega Chapter member induction |
| 2011 | Finalists for the George Washington School of Public Health and Health Sciences Oral Presentation at GWUMC Research Day |

## PUBLICATIONS AND REPORTS

### Published abstracts

Diaz Olavarrieta C, Ganatra B, Seuc A, Villalobos A, **Karver T,** Sorhaindo A, García S, Pérez M, Bousieguez M, Sanhueza P. (2014). Can nurses offer early medical abortion as safely and effectively as physicians? A randomized controlled noninferiority trial in Mexico City public legal abortion facilities. *Contraception*; 89(5):479.

**Karver T,** Sorhaindo A, García S, Diaz Olavarrieta C. (2014). Has public opinion on elective abortion changed amongst the Mexican population? Policy and practice implications of the 2013 National Public Opinion Survey on Abortion. *Contraception*; 89(5):481.

### Under review

Kerrigan D, Barrington C, **Karver T,** Davis W, Donastorg Y, Perez M, Gomez H, Mbwambo J, Likindikoki S, Galai N, Chan KS. Development and Implications of a Sex Work Stigma Scale (SWSS) among Female Sex Workers Living with HIV in the Dominican Republic and Tanzania using Item Response Theory. (Manuscript under review by co-authors).

Beckham SW, **Karver TS,** Shembilu C, Donastorg Y, Perez M, Gomez H, Barrington C, Mwampashi A, Likindikoki S, Mbwambo J, Kerrigan D. Acceptability and Perceptions of HIV Oral Self-Testing Across Settings: A Comparative Qualitative Study among Dominican and Tanzanian Female Sex Workers. (Manuscript under review by co-authors).

**Refereed research articles**

Kerrigan D, Murray M, **Sanchez Karver, T**, Mantsios A, Walters N, Hudson K, Kaplan-Lewis E, Pulido F, Bassa AC, Margolis D, Galai N. (2020). Feasibility of implementing long-acting injectable anti-retroviral therapy to treat HIV: a survey of health providers from the 13 countries participating in the ATLAS-2M trial. *AIDS Res Hum Retroviruses,* doi: 10.1089/AID.2020.0208.

Murray M, Kerrigan D, Hudson KJ, Walters N, **Karver TS,** Mantsios A, Galai N. (2020). Identifying appropriate candidates for long-acting antiretroviral therapy: findings from a survey of health care providers in the ATLAS-2M trial. *HIV Res Clin Pract,* 21(4):105-113.

Kerrigan D, **Sanchez Karver T,** Muraleetharan O, Savage V, Mbwambo J, Donastorg Y, Likindikoki S, Perez M, Gomez H, Mantsios A, Murray M, Beckham SW, Davis W, Galai N, Barrington C. (2020). "A dream come true": Perspectives on long-acting injectable antiretroviral therapy among female sex workers living with HIV from the Dominican Republic and Tanzania. *PLoS One*, 15(6): e0234666.

Mantsios A, Murray M, **Karver TS,** Davis W, Margolis D, Kumar P, Swindells S, Bredeek UF, Deltoro MG, García RR, Antela A, Garris C, Shaefer M, Gomis SC, Bernáldez MP, Kerrigan D. (2020). "I feel empowered": women's perspectives on and experiences with long-acting injectable antiretroviral therapy in the USA and Spain. *Cult Health Sex* 21:1-13. doi: 10.1080/13691058.2020.1752397.

Mantsios A, Murray M, **Karver TS,** Davis W, Margolis D, Kumar P, Swindells S, Bredeek UF, García Del Toro M, Garcia Gasalla M, Rubio García R, Antela A, Hudson K, Griffith S, Kerrigan D. (2020). Efficacy and Freedom: Patient Experiences with the Transition from Daily Oral to Long-Acting Injectable Antiretroviral Therapy to Treat HIV in the Context of Phase 3 Trials. *AIDS Behav*, doi: 10.1007/s10461-020-02918-x.

Davis W, Mantsios A**, Karver T,** Murray M, Punekar Y, Ward D, Bredeek UF, Moreno S, Merino D, Knobel H, Campis A, Kerrigan D. (2020). "It made me more confident that I have it under control": Patient and provider perspectives on moving to a two-drug ART regimen in the United States and Spain. *PLoS One*, 15(5): e0232473.

Kerrigan D, Donastorg Y, Barrington C, Perez M, Gomez H, Mbwambo J, Likindikoki S, Mantsios A, Beckham SW, Leddy A, **Karver TS,** Galai N, Davis WW. (2020). Assessing and Addressing Social Determinants of HIV among Female Sex Workers in the Dominican Republic and Tanzania through Community Empowerment-Based Responses. *Curr HIV/AIDS Rep.* 17(2):88-96.

Sorhaindo AM, **Karver TS,** García SG, Karver JG, Diaz Olavarrieta C. (2016). Constructing a validated scale to measure community-level abortion stigma in Mexico. *Contraception*, 93(5):421-31.

**Karver TS,** Sorhaindo AM, Wilson K, Contreras X. (2016). Exploring intergenerational changes in perceptions of gender roles and sexuality among indigenous women in Oaxaca. *Culture, Health & Sexuality*, 18(8):845-59.

Diaz Olavarrieta C, Ganatra B, Sorhaindo AM, **Karver TS,** Seuc A, Villalobos A, Garcia SG, Pérez M, Bousieguez M, Sanhueza P. (2015). Nurses delivery of early medical abortion in Latin America: A randomized controlled noninferiority trial comparing nurse provision of early medical abortion to physician provision in Mexico City. *Bulletin of the World Health Organization,* 93:249-258.

Montoya-Romero JJ, Schiavon R, Troncoso E, Díaz- Olavarrieta C, **Karver T.** (2015). Induced abortion in Mexico: What do Mexican Ob/Gyn know, think and do. *Ginecología y Obstetricia de México*; 83:23-31.

Díaz Olavarrieta C, Valencia J, Wilson K, García SG, Tinajeros F, **Sanchez T.** (2011). Assessing the effectiveness of a patient-driven partner notification strategy among pregnant women infected with syphilis in Bolivia. *Sexually Transmitted Infections,* 87(5):415-9.

Contreras X, van Dijk MG, **Sanchez T,** Smith PS. (2011). Experiences and Opinions of Health-Care Professionals Regarding Legal Abortion in Mexico City: A Qualitative Study. *Studies in Family Planning,* 42(3):183-190.

**Research reports**

Bell K, Moore KA, Terzian M, Knewstub D, Lawner E, Humble J, **Karver TS**, Bandy T. (2012). Improving the lives of adolescents and young adults: Out-of-School Time Programs That Have Significant Positive Impacts. Washington, DC: Child Trends.

Redd Z, **Karver TS,** Murphey D, Moore KA, Knewstub D. (2011). Two Generations in Poverty: Status and Trends among Parents and Children in the United States, 2000-2010. Washington, DC: Child Trends.

**Sanchez TY,** Lehman T. (2011). Complementary and Alternative Medicine Inventory Summary of Cancer Center Programs and Integrative Medicine Programs. Submitted to the National Cancer Institute. Washington, DC: Academy for Educational Development.

Hanlon E, Goodman AS, **Sanchez TY.** (2010). Topline Report of Interviews with Cooperative Groups. Submitted to the National Cancer Institute. Washington, DC: Academy for Educational Development.

Planas L, **Sanchez TY.** (2010). Formative Research on NCI's Spanish-language Informed Consent Template for Chemoprevention Clinical Trials and the Informed Consent Process with Spanish-Speaking Populations. Submitted to the National Cancer Institute. Washington, DC: Academy for Educational Development.

Lehman T, **Sanchez TY,** Planas L. (2010). Subscriber Evaluation of the NCI Cancer Bulletin. Submitted to the National Cancer Institute. Washington, DC: Academy for Educational Development.

## REFEREED RESEARCH PRESENTATIONS

Mantsios AR, Murray M, **Karver TS**, Davis W, Margolis D, Kumar P, Swindells S, Fritz Bredeek U, García del Toro M, Garcia Gasalla M, Rubio García R, Antela A, Hudson K, Griffith S, Kerrigan D. (October 2019). "I feel empowered": Women's perspectives on and experiences with long-acting injectable anti-retroviral therapy in the United States and Spain. Proceedings of the poster presentation at the 2019 IDWeek: Washington, DC.

Beckham SW, **Karver TS,** Shembilu C, Donastorg Y, Perez M, Gomez H, Barrington C, Mwampashi A, Likindikoki S, Mbwambo J, Kerrigan D. (December 2018). Acceptability and Perceptions of HIV Oral Self-Testing Across Settings: A Comparative Qualitative Study among Dominican and Tanzanian Female

Sex Workers. Proceedings of the poster presentation at the Dissemination and Implementation Science Conference: Washington, DC.

**Karver T,** Barrington C, Donastorg Y, Perez M, Gomez H, Mbwambo J, Likindikoki S, Shembilu C, Beckham B, Kerrigan D. (July 2018). "The society around us is the one that segregates us": A comparative exploration of sex work stigma among female sex workers living with HIV in Tanzania and the Dominican Republic. Proceedings of the poster presentation at the 22nd International AIDS Conference: Amsterdam, The Netherlands.

**Karver TS,** Donastorg Y, Perez M, Barrington C, Kerrigan D. (August 2017). Correlates of sex work stigma among female sex workers living with HIV in the Dominican Republic. Proceedings of the oral presentation at the CCAS Expert Summit: From Care To Cure - Shifting The HIV Paradigm: Douglas, Barbados.

Barrington C, **Karver T**, Donastorg Y, Perez M, Gomez H, et al. (August 2017). *"Son unas perras eso es lo que dicen":* A qualitative study exploring sex work stigma among women living with HIV in the Dominican Republic. Proceedings of the oral presentation at the CCAS Expert Summit: From Care To Cure - Shifting The HIV Paradigm: Douglas, Barbados.

**Karver TS,** Rimal RN, Alves B, Mehndiratta S, Dominguez Gonzalez K, Lopez Dodero A, Alveano Aguerrebere S, Langelan M. (November 2015). Experience and perceptions of gender-based violence against women in public transportation: The Case of Mexico City. Proceedings of the poster presentation at the American Public Health Association's 143rd Annual Meeting and Exposition: Chicago, IL.

Rosado B, **Karver TS,** Cleary S. (November 2015). Sexual Health Advocates, Promoters and Educators (SHAPE): Development of a comprehensive sexual health curriculum and peer education program for U.S.-based Latino adolescents using a community-based participatory research approach. Proceedings of the round table discussion at the American Public Health Association's 143rd Annual Meeting and Exposition: Chicago, IL.

McDonnell KA, **Karver TS,** Andrade E, Edberg MC. (November 2015). Proyecto VOCES: Listening to the voices of Latinas to prevent gender based violence. Proceedings of the poster presentation at the American Public Health Association's 143rd Annual Meeting and Exposition: Chicago, IL.

Sorhaindo AM, **Karver TS,** García SG, Karver JG, Diaz Olavarrieta C. (August 2014). Constructing a validated scale to measure community-level abortion stigma in Mexico. Proceedings of the oral presentation at the CLACAI IV Regional Conference: Lima, Peru.

Sorhaindo AM, **Karver TS,** García SG, Karver JG, Diaz Olavarrieta C. (June 2014). Constructing a validated scale to measure community-level abortion stigma in Mexico. Proceedings of the oral presentation at the IUSSP Seminar on Decision-making regarding abortion—determinants and consequences: Nanyuki, Kenya.

Ruiz MJ, Munguia A, van Dijk M, Garcia S, **Karver TS.** (October 2012). Intercultural maternal health care services in Guatemala. Proceedings of the poster presentation at the American Public Health Association's 140th Annual Meeting and Exposition: San Francisco, CA.

**Karver TS,** Bell K, Terzian MA, Moore KA. (July 2012). Healthy Development in Young Adulthood: Getting and Staying "On Track." Proceedings of the plenary presentation at the 2012 Add Health Users Conference: Bethesda, MD.

**Karver TS,** Wilson K, Contreras X, García SG, McDonnell KA. (October-November 2011). Exploring changing intergenerational social values surrounding sexuality among rural and indigenous Oaxacan women. Proceedings of the poster presentation at the American Public Health Association's 139th Annual Meeting and Exposition: Washington, DC.

**Sanchez TY,** Wilson K, Contreras X, García SG, McDonnell KA. (March 2011). Exploring changing intergenerational social values surrounding sexuality among rural and indigenous Oaxacan women. Proceedings of the poster presentation at the George Washington University Research Day: Washington, D.C.

Salazar SI, Planas L, **Sanchez TY.** (November 2010). Formative Research Findings from the National Cancer Institute on the Development of a Clinical Trial Informed Consent Template for Spanish Speakers. Proceedings of the round table discussion at the American Public Health Association's 138th Annual Meeting and Exposition: Denver, CO.

## PROFESSIONAL AFFILIATIONS

| | |
|---|---|
| 2011 – Present | American Public Health Association |
| 2014 – Present | Delta Omega Public Health Honorary Society, Omega Chapter at the George Washington University Milken Institute School of Public Health |
| 2018 – Present | International AIDS Society |

## COMPUTER AND ANALYTICAL SKILLS

- PowerPoint, Excel, and other Office applications (Advanced)
- Stata (Advanced)
- Statistical Analysis Software (SAS) (Advanced)
- Statistical Package for the Social Sciences (SPSS) (Advanced)
- NVivo (Advanced)
- Dedoose (Advanced)
- Atlas.ti (Advanced)

## LANGUAGE SKILLS

- Bilingual fluency (native) in both Spanish and English